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### Experiences of Mothers of Children with Autism and Aggression : The Process of Becoming "Super-Copers"

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MONTCLAIR STATE UNIVERSITY

EXPERIENCES OF MOTHERS OF CHILDREN WITH AUTISM AND AGGRESSION:  
THE PROCESS OF BECOMING "SUPER-COPERS"

by

CHRISTINE PETERS

A Master's Thesis Submitted to the Faculty of  
Montclair State University

In Partial Fulfillment of the Requirements


For the Degree of  
Master of Arts

January 2014

College of Education and Human Services

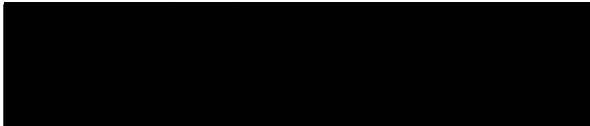
Department of Family and Child Studies

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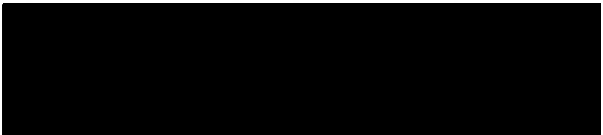
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EXPERIENCES OF MOTHERS OF CHILDREN WITH AUTISM AND AGGRESSION:  
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A THESIS

Submitted in partial fulfillment of the requirements

For the degree of Masters of Arts

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CHRISTINE PETERS

Montclair State University

Montclair, New Jersey

January 2014

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### **Abstract**

The purpose of this qualitative study was to explore the experiences of 14 mothers who have children with Autism and aggression issues. The combination of marginalization, stigma and the impact of aggression were found to be an overarching theme with emotional effects of fear, despair, guilt and anxiety being experienced by the mothers. Using grounded theory and feminist disability theory, a process of coping emerged which included analyzing for aggression triggers, as well as searching and utilizing resources. The end result of this model was mothers becoming advocates or maintaining a level of coping. A significant finding of this study was the mothers' lack of access to formal and community supports by school professionals. A lack of consistent protocols regarding when their child is restrained in school and possible police intervention was also noted by these mothers. Implications for school professionals and future research are discussed.

Dedicated to my husband

Joe Peters

my source of support, and to my son

Joey Peters

who has taught me more about myself

than I could have ever imagined.

## **Acknowledgements**

This thesis would never have come to fruition without the expertise of Dr. Christine Price. Although she had no previous knowledge of families with children with Autism, she enthusiastically embraced this challenging topic. She had faith in me to conduct qualitative methods and taught me how to do it. She generously gave of her time and applauded my efforts.

My thesis committee members, Dr. Olena Nesteruk and Dr. Alicia Broderick, also generously supported my efforts. Coming from two different fields, they brought levels of insight to my research that enabled me to thoroughly address this personal and important topic. I would like to also thank each of my professors that I have had during the past two years; they all encouraged me and taught me so much.

Finally, I want to thank the 14 mothers who graciously shared their stories with me; they held nothing back knowing I was one of them. They all understood the importance of having our voices heard so we can be empowered to do just one thing – help our children achieve success.

### **Personal Statement**

Seventeen years ago I became the mother of a son who was diagnosed with Autism at the age of three years. By the time my son was in first grade, we began to experience aggression issues both at home and in school. As my son grew in size and strength, so did his aggressive episodes. Although I became very knowledgeable in most areas of Autism, nothing prepared me for what we began to experience.

When I reached out to local or online Autism support groups I was unable to find other mothers who also had a child with Autism and aggression. Many other mothers expressed shock at some of the aggression we were experiencing, stating that their Autistic child would not hurt a bug, never mind another person. I was nervous to attend story time at the library or play dates since I was not always sure what would trigger my son's aggression. One of my biggest fears was that he would hurt another child. I had desperate feelings that I was chained forever to a monster.

Many of the teachers and therapists in the different schools my son attended were not very supportive. The fact that two different private special education schools expelled him due to his aggression did not help my feelings of helplessness and growing depression. Occasionally I came in contact with a behaviorist or teacher that seemed to recognize that his aggressive acts may be part of his Autism, and they would assist my husband and I in ways to handle his challenging behaviors using behavioral modification techniques. Eventually we found a psychiatrist who prescribed medication to help stabilize my son's mood and impulsivity. Despite these medications, we are never very far from the next aggressive outburst. Through the years no teacher, therapist or doctor has ever asked me if I was alright or offered me access to a support system that could

help my depression. As a result, my feelings of isolation and marginalization were continually reinforced.

I have often been curious to discover if my experience is unique or if other mothers of a child with Autism and aggression have had similar experiences with their schools and community. I hope this study will expose the collective experiences of other mothers in my situation so that we do not have to suffer alone but instead, help provide access to supports that will sustain us so we can continue to help our children.



## Introduction

*Sometimes the strength of motherhood is greater than natural laws.*

-Barbara Kingsolver

Motherhood traditionally brings much joy into the life of a woman, along with much work, worry and lack of sleep. Most women will rise to the occasion when given the opportunity to raise a child, and most will admit they are doing the best they can since children do not come with instructions.

Traditionally, becoming a mother has been viewed as a life-changing event filled with feelings of euphoria, gratitude, and love. Throughout Western society the birth of a child with a disability, however, is commonly regarded as a tragic event, one that overwhelms all aspects of a mother's life. Families raising children with disabilities are often portrayed as damaged and parents who experience feelings of guilt, denial, displaced anger, and chronic sorrow often dominate the research literature (Ferguson, 2002). Over the past 50 years, researchers have shifted their view of disability away from the medical model toward a perspective that highlights the social processes that shape the experiences of individuals with disabilities or a family of a child with a disability (You & McGraw, 2011). Much of this shift took place in response to the large and growing disability rights movement, which urged parents to move beyond their grief which is both damaging to themselves and to their child (Sinclair, 1993). Researchers now focus on themes of stress and coping or how families adapt to raising a child with a disability (Ferguson, 2002).

Fifty years ago Goffman (1963) discussed the myths, fears and misunderstandings that society attaches to people with disabilities *and* their family members. He posited that

individuals with disabilities experience stigma, a social process that dishonors and shames them. He also argued that family members and friends experience stigma via their close ties with those that have disabilities. Mothers, in particular, that are raising a child with a disability experience firsthand unique challenges relating to marginalization and stigma. Mothers of a child with Autism inevitably fall into this disenfranchised group (You & McCraw, 2011).

What is culturally desirable in mainstream Western society is the notion of strong, healthy, independent, and competent individuals. Mothers of children with disabilities, including Autism, are constantly reminded of these standards and cultural expectations. They often struggle with the reality that their children may not meet these attributes in the way society dictates them. The constant barrage of separate programs for “special needs” children, the need for separate therapies and specialists, and special education itself all serve as reminders that their child is different from societal norms. As long as society continues to reinforce these competency norms, both women and the disabled, by virtue of their more dependent and vulnerable constitutions, will remain oppressed, undervalued, and function as second class citizens (Grassie, 2009).

These socially constructed concepts of oppression and stigma among disabled people became the model of feminist disability theory. Through feminist disability theory we can look at the role of mothers of children with Autism as oppressed women due to patriarchy, as marginalized due to the deviant standing of their disabled children by society, and as undervalued due to their caretaker role (Grassie, 2009). Mothers of children with Autism will experience marginalization whether they realize it or not by association with their child who is disabled. Marginalization arises from social

institutions and is felt in subjective experience; it is about one's place and participation in social life (Charmaz, 2008). Suffering underlies feelings of being marginalized when people feel relegated to the edges of society or condemned to an underserved fate. Marginalization reflects a fundamental form of suffering that comes with a loss of self. Studies of marginalization can join objective realities with subjective experience. Further analyses of suffering complements learning how, when and why people become marginalized (Charmaz, 2008).

Some children with Autism also experience behavioral challenges and aggression (Hodgetts, Nicholas & Zwaigenbaum, 2013; Kanne & Mazurek, 2011; Mazurek, Kanne & Wodka, 2013). As a result, mothers of children with Autism that demonstrate behavioral challenges have the potential to be marginalized three times; (1) due to their female gender and caretaker role; (2) due to their association with their disabled child, and (3) due to the aggression their child may exhibit since aggression is an antisocial behavior. In addition to experiencing marginalization, mothers of children with Autism may also experience feelings of isolation, depression, helplessness, anger and inadequacy (Boyd, 2002; Manning, Wainwright & Bennett, 2011; Singer, Ethridge & Aldana, 2007).

### *Rationale*

Because mothers of children with Autism are at greater risk both psychologically (i.e., depression, anger, helplessness) and socially (e.g., isolation, marginalization) it is critical researchers examine their unique experiences and explore avenues of support and resilience. Existing research on mothers of children with Autism finds these mothers are at great risk for depression which directly impacts their mothering experience. Singer,

Ethridge and Aldana, (2007), for example, found 35% of mothers of children with Autism had elevated levels of depression, more than mothers of children with other disabilities. Mothers exhibiting elevated depressive symptoms were found to interact less with their children, were more irritable and were more likely to use explosive discipline than mothers without elevated depressive symptoms. If a child with Autism also demonstrated problem behavior (e.g., aggression, self-injury) then mothers were found to be at an even greater risk for depression (Boyd, 2002; Manning, et al., 2011; Singer, et al, 2007). Research documenting the experiences of mothers of children with Autism and aggression when compared to mothers of children with Autism only found the mothers of aggressive Autistic children to be the most distressed (Gray, 2002). Smith, Seltzer, Tager-Flusberg, Greenberg and Carter (2008) found that mothers of adolescents with Autism experience chronic stress comparable to combat soldiers; "the mothers of children with high levels of behavior problems have the most pronounced physiological profile of chronic stress, but the long-term effect on their physical health is not yet known" (p. 884). In addition, the behavioral challenges often associated with Autism can leave families feeling isolated which increase feelings of marginalization (Plumb, 2011).

Unfortunately, recent research on violent behaviors in children with Autism reveals aggression is much more prevalent than previously thought. Results of a study done by Mazurek, et al., (2013) showed a 53 % prevalence rate of aggression among 1584 children and adolescents with Autism. In addition to the prevalence rate, this study also looked at relative contributions of common problems to the prediction of aggression among children with Autism, such as the interruption of repetitive behaviors. Consequently, this higher prevalence rate of aggression among children with Autism also

signifies that more mothers are being affected as evidenced by alarming rates of depression, stress and isolation among mothers of children with Autism (Boyd, 2002).

Social support has been found to be a buffer against family crisis, as well as a mediator of family distress (Boyd, 2002). Mothers of children with Autism and other disabilities who perceived higher levels of informal and formal social support reported lower levels of depression, anxiety and anger (Dunn, Burbine, Bowers & Tantleff-Dunn, 2001; Plumb, 2011). Furthermore, the inability to locate or access social support can affect a mother's overall wellbeing (Plumb, 2011). A lack of social support can lead parents to withdraw from the larger community (Boyd, 2002), which can increase levels of isolation and marginalization.

In summary, mothers of children with Autism demonstrate higher rates of depression and stress than parents of children with other disabilities. Research shows that a child with Autism and aggression can increase the risk of depression for mothers. Although supports can buffer the effects of depression, the inability to locate or access social supports can negatively impact these mothers, increasing their feelings of isolation and marginalization. How can mothers of children with Autism and aggression find the supports they need that can help them cope? Are schools in a position to provide support or access to support systems for these mothers? By heightening awareness and creating dialogue about this issue, it was the intent of this researcher to better understand the experiences of mothers with children with Autism and aggression and suggest ways to improve practice relating to social and community support. Exploring the experiences of these mothers provided foundation knowledge to form a grounded theory about the

processes they endure with their child, school and community and what they feel will best help them to gain resiliency.

### *Statement of Purpose*

The purpose of this exploratory study was to investigate the experiences of mothers of children with Autism and aggression and to understand the processes they undergo with their children's school and the larger community. The intent was to learn through the narratives of mothers of children with Autism and aggression and to better understand how their experiences impact them personally. Based on existing research, it was expected that themes of isolation, marginalization, stress, and depression would be revealed in addition to themes of coping and resiliency, and others that may not yet be documented. My plan was to collect information about how the schools and/or community handle Autistic children's aggressive behaviors and respond to families' need for support. This information was used to construct a theory of support protocols that can improve the institutional practices that may or may not be currently in place.

## **Review of Literature**

### **Prevalence of Autism**

Autism is a neurodevelopmental disability that affects communication, social development, and interpersonal behaviors. It is also referred to as Autism Spectrum Disorder (ASD) because the idea of a spectrum helps to illustrate how it affects each person individually with wide degrees of severity (Autism Speaks, 2013). The newly announced prevalence rate for Autism by the Center for Disease Control that 1 in 88 children are born with Autism in the U.S. each year, suggests a considerable number of families are experiencing a high level of emotional and economic stress (CDC, 2012). In New Jersey the figure is higher at 1 in 49 and is among the highest in the nation, second only to Utah (Washburn, 2012).

Compared to families of typically developing children and families of children with other developmental disabilities, an Autism diagnosis can create unique stressors for families (Manning et al., 2011). While children with Autism can have social, communication or cognitive deficits, Autism self-advocates claim these are not to be viewed as deficits but part of 'neurodiversity' which recognizes variation as a natural part of the human genome (Jaarsma & Welin, 2012). Some children with Autism can have behavioral problems including tantrums, aggression and self-injury (Manning et al., 2011). Many children with Autism may also prefer constancy and routine which can restrict or disrupt family activities. Due to these challenges, families with a child with Autism are more likely to become socially isolated from other families with same-age



children. This isolation can lead to lower self-esteem and increased depression in these parents (Emerson 2003; Manning et al., 2011).

### *Prevalence of Aggression in Autism*

Within the Autism population are parents whose children have Autism *and* aggression issues. Multiply the stress of Autism with aggression and the result is a population of parents undergoing enormous pressure that makes families vulnerable to crisis. While there is little consensus of a definition of aggression and how to measure it, the perception of causing intentional distress or harm is consistent across most definitions (Hodgetts, et al., 2013). A ten year longitudinal study conducted by Gray (2002) found that the parents of children with Autism who were the most distressed were those whose children were aggressive and/or severely obsessive, a situation that worsened as their children became larger and more difficult to control. Although aggression was not the focus of his study, Gray (2002) did emphasize that among the families participating in his research, “they appeared to be the ones at greatest risk” (p. 32).

The fields of developmental psychology and psychopathology have provided a rich body of literature examining the roles of various risk and protective factors in predicting aggressive trajectories among children and adolescents (Kanne & Mazurek, 2011). Kanne and Mazurek (2011) were the first to report prevalence rates of and risk factors for aggressive behaviors among a large (N = 1380), national sample of youth with Autism. Their findings indicate that 68% of these youth with ASD had aggressive behaviors towards their caregivers and 49% had aggressive behaviors towards others. Further, they found several factors that have historically been shown to predict



aggression in typically developing children were not predictive of aggression in children with Autism. For example, children without Autism engaged in disruptive and or aggressive behaviors primarily for social goals, such as to gain attention, obtain items or to escape demands. In contrast, children with Autism engaged in disruptive and aggressive behaviors to escape demands that interfere with a repetitive behavior, in response to a panic attack or a psychomotor seizure, or to avoid idiosyncratic sensory stimuli (e.g., loud noises, fluorescent lighting, certain smells or being touched), all of which are unique traits common within Autism (Kanne & Mazurek, 2011).

A second study of prevalence rates of aggression in Autism by Mazurek, Kanne and Wodka (2013) found similar results. Specifically, they identified a 54% rate of aggression among two to four year old children with Autism and a 46% rate among children ages 14 – 17 years. The minimal decrease in aggression from childhood into adolescence shows that almost half of these children continue to be aggressive well into their teenage years, when they are larger and more difficult to control (Mazurek et al., 2013).

Aggression can be physically dangerous to the individual with Autism and others in the environment, limit access to treatment, interfere with learning, reduce opportunities for interpersonal relationships, increase hospitalization rates, and impede participation in everyday activities. In addition, aggressive behavior is the leading cause of residential placement, although paradoxically, it also can limit access to respite and residential programs (Hodgetts et al., 2013). The parents in the study by Hodgetts et al, (2013) reported that the aggression, not the core symptoms of Autism (i.e., deficits in socialization and communication), was the greatest challenge in living with and accessing

currently available supports and services for their child. The results of their study found the lack of professional knowledge, services, and resources to deal with aggression were crucial. It is interesting to note that these researchers also found no qualitative studies where the experiences of families of children with Autism and aggression were investigated.

### Impact of Autism on Families

Research has shown that parents of children with Autism experience greater isolation, depression, stress and strained marital relationships than parents of typically developing children or parents of children with other types of developmental delays (Dunn et al., 2001; Gray, 2002; Manning et al., 2011; Plumb, 2011; Singer et al., 2007). In addition, families with a child with Autism experience higher healthcare and childcare costs while also experiencing a loss of income, impacting their overall socioeconomic status (Baker & Drapela, 2010; Cidav, 2012; Montes & Halterman, 2008).

Luther, Canham and Cureton (2005) estimated that the cost of raising a child with a disability (including Autism) is approximately three times greater than the cost of raising a non-disabled child. Further, Montes and Halterman (2008) found the average loss of annual family income associated with having a child with Autism was \$6,200 or 14% of their reported income. Additional costs to the family can include difficulties maintaining employment, lost leisure time opportunities, less time available for other children in the family, and difficulty finding or paying for adequate child care (Luther et al., 2005).

A study done by Knestrict and Kuchey (2009) focused on finding characteristics of resilient families raising a child with severe disabilities (including Autism). The strongest finding they uncovered in their research was the importance of socioeconomic status and access to services (Knestrict & Kuchey, 2009). Additional research by Boyd (2002) found the three most stressful factors associated with parenting a child with Autism were: concern over the permanency of the condition, poor acceptance of Autistic behaviors by society and by family members, and the low levels of social support received by parents. Further research has identified experiences of isolation due to external sources (e.g. society's lack of understanding) as a major source of stress for families that have a child with Autism (Plumb, 2011). These findings represent processes external to the family's day-to-day existence that are determined by powers outside the family's control. Though parents have limited ability to change these external stressors, they have enormous impact on the daily events within a family (Knestrict & Kuchey, 2009).

For a small percentage of families facing life with an Autistic child, the devastating act of filicide occurs. Palermo (2003) discussed the rising rates of filicide in families with a child with Autism. Based on factors thought to motivate the murder, 56% of filicides are classified as altruistic or "murder committed out of love" and 16 – 29% are followed by the suicide of the mother. You and McGraw (2011) in their study of mothers raising children with Autism in South Korea, found that 6 out of 14 mothers reported having had thoughts of suicide. But these mothers added that if they had committed suicide, they also would have killed their children with Autism. While these women did not commit suicide or filicide, the fact that almost half of these mothers had

such thoughts is worth noting. Overall, Palermo (2003) notes that advocacy groups for the disabled and researchers in the field of ethics and disabilities warn of the rising numbers of altruistic filicides in the presence of a developmental disability yet this is the first published report on this alarming trend.

### *Impact of Autism on Mothers*

Mothers of children with Autism appear to be the most severely affected member of the family, with almost one third exhibiting depressive symptoms, with feelings of incompetence and decreased ability to cope (Baker & Drapela, 2010; Emerson, 2003). Mothers of children with Autism report less involvement in political, social, intellectual, and cultural activities which often serve as stress reducers to mothers of typically developing children (Boyd, 2002). Rodrique (2011) examined mothers of children with Autism and reported reduced family adaptability, lower assessments of parenting competence, and less marital satisfaction compared to mothers of children with Down syndrome and children without disabilities. Gender differences have been found in the personal impact that mothers and fathers experienced in their child's disability. Mothers, for example, were found to be directly and considerably affected by their child's Autism while fathers claimed the effect to be indirect such as experiencing stress through their partners (Tehee, Honan & Hevey, 2009). Having a child with Autism was the best predictor of poor father involvement, highlighting the aggravating effect of Autism on the marital relationship (Tehee et al., 2009).

While increased use of home-based care has the potential to benefit the child with Autism, and to reduce health costs, home-based care places substantial financial and time

pressures on mothers (Sawyer, Bittman, La Grecca, Cretenden, Harchak & Martin, 2010). The additional time demands of caring for a child with Autism may lead mothers to restrict time that previously was available for other activities including paid employment, time with their spouse, time with other children, hobbies, recreation, or sleep. This has the potential to adversely affect the psychological adjustment and the quality of life of mothers (Sawyer et al., 2010). In a study by Sawyer et al. (2010), 92% of mothers reported feeling under stress and lacking time to complete activities and 59% reported they lacked time to spend with family members and friends. Overall, the study found that mothers spend on average, six hours per day caring for their child with Autism.

The results of the study done by Cidav (2012) found that having a child with Autism is associated with substantially reduced earnings of mothers. Mothers of children with Autism earn on average 35% less than mothers of children with other disabilities and 56% less than mothers of children with no disabilities (Cidav, 2012). Often the mother's employment is severely affected by having a child with Autism. Specifically, 60% of respondents in a study done by Baker and Drapela (2010) were not employed due to having a child with Autism, 53% worked fewer hours to accommodate the needs of their child, and 23% had not taken a promotion at work due to the same reason.

#### *Mothers as Caregivers*

Mothers continue to be the primary caregivers and advocates for their children in daily life, and this is perhaps even more likely in the case of children with disabilities (Read, 2000; Rocque, 2010). Emerson (2003) conducted interviews of the primary caregivers of a child with Autism and found that 94% of the primary caregivers were

mothers. Because mothers provide the majority of care to Autistic children, it is evident that they will be more significantly affected as compared to other family members.

Many people who are providing assistance and care to family members do not recognize themselves as caregivers, which includes mothers caring for a child with Autism. Feinberg, Wolkwitz and Goldstein (2006) studied a project in Maine that works with health care practitioners to develop assessment systems which can help individuals to self-identify as family caregivers and refer them to caregiver specialists in the community. By proactively identifying family caregivers, including mothers of children with Autism, in primary care physician's offices, family caregiver support programs can reach caregivers before they experience any adverse effects from caregiving. In addition to decreasing the isolation and ill-effects of caregiving, this support may also delay the institutionalization of those receiving care (Feinberg, et al., 2006). The value of systematic assessment of family caregivers' needs stems in part from recognition of the fundamental need to sustain caregiving families and help them to "stay on the job." Family caregivers may suffer from physical, emotional, and financial problems that impede their ability to give care now and support their own care needs in the future. Without attention to their needs, their ability to continue providing care may be jeopardized (ARCH, 2012).

Mothers raising a child with Autism are equally at risk as full-time caregivers of other types of care recipients. A survey conducted by The National Alliance for Caregiving (2009) found that 31% of caregivers described themselves as highly stressed and 17% had fair or poor health, two thirds were emotionally drained and one third suffered from depression. The mental and physical health of the caregiver cannot be

understated as care recipients may be at risk for encountering abuse from caregivers when recipients have a pronounced need for assistance and when caregivers have pronounced levels of depression, ill health, and distress (ARCH, 2012). All mothers of Autistic children will only be able to provide effective care for their child if their own health does not become compromised by their child's disability. Therefore studying the effects of various support systems that can enable the caregiver abilities of mothers is needed (Sawyer et al., 2010).

### Feminist Disability Theory

The general disadvantages and discrimination experienced by disabled people are simply exacerbated for disabled women. Disabled women struggle with both the oppressions of being women in male-dominated societies and the oppressions of being disabled in societies dominated by the able-bodied (Wendell, 1989). It is not the physical or mental impairment of the individual which disables, but instead the handicapping effects of a society geared to the norm of being 'able-bodied.' The disablement is therefore socially created and the experience of disability is another form of social oppression (Lloyd, 1992). Mothers of children with Autism surrender to this role rather than question it, in order to conform to their dominant cultural agenda (Grassie, 2009).

How gender and disability are experienced, is shaped by symbolic and material practices that evolve over time within particular historical and political contexts (You & McGraw, 2011). Critical feminist theory attempts to explain women's historical oppression by accounting for political, economic, cultural, and psychological forces that support it. Disability theory argues that the inferior social status given to individuals with



disabilities does not result from bodily or psychological defects, but rather to the myths, fears, and misunderstandings that society attaches to them (You & McGraw, 2011). Feminist disability theory incorporates the socially constructed oppression of women with the socially perceived inferiority and resulting oppression of being disabled. Mothers of children with Autism experience the socially constructed inferior and oppressed status of a disabled woman, by association of their children who are disabled with Autism. Other researchers have referred to this as 'disablement by proxy' (Brett, 2002; Read, 2000; Rocque, 2010). Brett (2002) noted that all parents in her study reported having felt that their child *and* themselves were labeled as disabled by society, and consequently found themselves in a situation constrained by societal and environmental boundaries. These parents further discussed social oppression and how their child's impairment was 'transplanted' to themselves as a parent (Brett, 2002).

The study by Read (2000) found that having a disabled child had such a fundamental impact upon the lives of mothers that their overall outlook on life was irrevocably changed. This impact also separated these mothers from other people who did not have the same experience of disability which drove them to try to make people understand the differences of being abled and being disabled. Read (2000) contends that the very process of trying to explain these differences and finding that people still cannot relate, can create an even greater barrier which can confirm their isolated and excluded position still further.

Research suggests that for many mothers having a disabled child is unexpected or undesired and involves a journey that was not anticipated (Ryan & Runswick-Cole, 2008). Baby care manuals and pregnancy books present the overall message that



‘disability is unlikely, undesirable and to be avoided at all costs’. Mothers, therefore, come to the experience as ‘others’, rather than ‘the wise’ (Ryan & Runswick-Cole, 2008). Greenspan (1998) argues that mothering a disabled child is fundamentally a different experience to mothering a non-disabled child and that this difference should be acknowledged. Yet it can be difficult to articulate the experiences of raising a disabled child without effectively confirming the views of others that to have a disabled child is a terrible thing (Ryan & Runswick-Cole, 2008). The danger is that by attributing extraordinary characteristics to the family, they cease to be ‘ordinary’, and without the status of ‘ordinary’ the disabled family is no longer regarded as having the same rights and aspirations as other families. The categorization and stigmatization of families of children with disabilities constructs them as ‘others’ (Ryan & Runswick – Cole, 2008).

The study by Gray (1993) found that most parents perceived themselves to be stigmatized by their child’s Autism, especially while in public. Public encounters are situations where the competence of parents is most open to question, and mothers were found to be more susceptible since they are generally responsible for domestic tasks, such as food shopping. Expectations violated by children with Autism are among some of the most basic rules of social interaction; the destruction of property, violations of personal space and inappropriate toileting represent severe tests for any parent attempting to negotiate a public outing. Whether the criticism expressed by strangers was direct or inferred, all parents reported that dealing with difficult public encounters was problematic since their abilities as parents were seemingly doubted (Gray, 1993). Rocque (2010) found parents tried to mediate these ‘embarrassing’ situations, because children are extensions of their parents and parents are often blamed for their behaviors. This

‘emotion management’ is an attempt to manage their own identity and to protect themselves from stigma at the same time helping the unfamiliar person manage their own feelings (Rocque, 2010).

### *Marginalization*

Marginalization occurs in relation to boundaries or barriers, distance or separation, and division or difference. Disconnection, devaluation, discrimination, and deprivation exemplify experiences of marginalization (Charmaz, 2008). Disabled people are viewed by society as “the other;” their bodies symbolize failure of control and the threat of pain, limitation, dependency, and possible death. People learn to identify with their own strengths based on cultural standards familiar to them and as a result can learn to hate, fear and neglect their own weaknesses (Wendell, 1989). Marginalized individuals feel disconnected, and moreover, see themselves as less worthy than other people (Charmaz, 2008).

Motherhood can be defined as a culture since it has its own attitudes and behavioral characteristics. Some of the characteristics mothers instantly relate to are the joys, frustrations and the intense emotional bonds felt for their children. Mothers also seek advice, guidance and support from each other as part of a shared identity associated with motherhood (You & McCraw, 2011). Mothers often share the experience of having partaken in a ‘rite of passage’ as motherhood is often viewed by society as a sign of adulthood and womanhood. Giving birth to children is also viewed by mothers as a daunting adventure bringing shared experiences that reinforces the association to their culture. Mothers of an Autistic child experience attitudes and behaviors based on the

characteristics of belonging to this social group that is unique to the ways of life of raising an Autistic child. They can be considered a subculture of motherhood, which implies all the marginalization that comes with not belonging to the dominant culture, as Greenspan (1998) states “to be a mother of a disabled child is to be different – a mother because she undoubtedly has a child, yet somehow not a mother in terms of the conventional notions of motherhood that pervade our society” (p.121).

Mothers of disabled children have occupied a complex, contradictory, and marginal position within both disability studies and the disabled people’s movement (Ryan & Runswick-Cole, 2008). This marginalization is related to the (often) non-disabled status of the mothers which propels them into the difficult and contentious debates about the role of non-disabled people within the lives of disabled people and within disability studies. At best, parents have been described as ‘allies’ of their disabled children. Ryan and Runswick-Cole (2008) argue that the mothers of disabled children are more than allies, as they experience directly and by proxy many of the discriminatory practices and attitudes that their disabled children face. Parents, too, experience the psycho-emotional aspects of disabled-ism as they begin to ‘know their place’, moderate their behavior, and learn to internalize the oppression (Ryan & Runswick-Cole, 2008).

The status of mothers in society is defined in relation to their children with disabilities, and as a result, these women are marginalized along with them. If the children are seen as “less than,” the mothers are marginalized as well. This creates various types of social exclusion related to disability status resulting in the mother experiencing disability vicariously due to their caretaker role (Grassie, 2009). The problems of living with a disability (or living with a child with a disability) are not

private problems, distinguishable from the rest of life and the rest of society. They are problems which can and should be shared throughout the culture as much as we share the problems of love, work and family life (Wendell, 1989).

### Family Resilience Theory

While mothers of children with Autism and aggression may face stigma, oppression and marginalization within their communities, they also find ways to adapt to their roles by the use of protective factors and resilience. Family Resilience theory is based on the work of Walsh (1998, 2002) which builds on a competence-based and strength-oriented family paradigm that allows a greater understanding of how families display resilience when challenged by adversity (Benzies & Mychasiuk, 2008; Brown, Howcroft & Muthen, 2010; Plumb, 2011). Family resilience can be defined as characteristics, dimensions, and properties of families which help them to be resilient to disruption in the face of change and adaptive in the face of crisis situations (McCubbin, 1998). The study of resilience stems from the empirically based knowledge of human behavior and contributes to the strengths-based philosophy of care and counseling (Plumb, 2011).

The Resiliency Model conceptualizes the demands, resources, and developmental issues involved in family life from a holistic perspective (Luther et al., 2005). Family resiliency theory has been used extensively to study families at risk and research has found that having a child with Autism can cause extreme stress in a family (Luther et al., 2005). Families that adapt successfully tend to have traits of resiliency, good coping skills, and informal and formal social support from the community (Luther et al., 2005).

Applying a strength-based approach portrays families facing crisis as challenged rather than damaged, and as successful as opposed to deficient (Brown et al., 2010; Walsh, 2002). Families need support to evaluate their patterns of functioning and to determine which patterns have to be discarded, retained, or restored. Often new patterns of functioning have to be adopted to facilitate adaptation to the crisis (Brown et al., 2010; Bryan, 2003). The Resilience Model is based on the belief that we can identify the traits or factors that make some individuals resilient to adversity and then develop these traits or alter these factors in those who are not so resilient (Bryan, 2003).

#### *Protective Factors*

Bronfenbrenner (1990) devised the socio-ecological model which pays explicit attention to the social, institutional, and cultural contexts of people-environment relations. The socio-ecological model is applicable to the processes and conditions that govern the lifelong course of human development in the environment in which human beings live. The environments of the socio-ecological model are the microsystem (family, peers), mesosystem (school, religion, neighborhood), and exosystem (politics, mass media, industry). While all families are affected by their microsystem, mesosystem, and exosystem, families with a child with Autism can be more interdependent within their meso and exo-systems due to receiving various types of support through special education schools and county or state government agencies. Family resiliency is optimized when protective factors are strengthened at all three interactive levels of the socio-ecological model (Benzies & Mychasiuk, 2008; Knestrict & Kuchey, 2009). Human development is seen as affected by not only within person characteristics (i.e. temperament, genetics and health) but also by external factors such as support systems,

political and cultural influences. It is this constant dynamic interaction that shapes the development of the child and the family (Knestrict & Kuchey, 2009).

Benzies and Mychasiuk (2008) identified and organized key protective factors that function across individual, family and community levels using the socio-ecological framework designed by Bronfenbrenner (1990). They organized 24 protective factors into three categories; individual, family, and community. Some of the 24 protective factors they list are: locus of control, self-efficacy, coping skills, belief systems, family cohesion, communication, social support and involvement in the community (Benzies & Mychasiuk, 2008). A few of these protective factors – family cohesion, communication, social support, and coping skills – are commonly studied by other researchers (Amatea, Smith-Adcock & Villares, 2006; Brown et al., 2010; Canary, 2008; Dunn et al., 2001). The concept of re-framing is also a popular protective factor and is suggested by still more researchers (Amatea et al., 2006; Heiman, 2002; Luther et al., 2005). Re-framing relates to the family's perception of stressful experiences and entails re-defining personal and family goals and priorities to help families cope. The concept of reframing has been applied to families challenged by Autism (Luther et al., 2005). Similar to the concept of reframing, is the concept of recognizing the child first, which is a concept used among families with a child with a disability. Researchers found that the more resilient families are the ones that are able to see the child first and the disability second (Barnett et al., 2003; Knestrict & Kuchey, 2009).

In spite of the plethora of protective factors that have been identified by researchers, it is important to identify which factors can be effectively taught to parents of a child with Autism and aggression. The study by Knestrict and Kuchey (2009) found

that resiliency in families with a child with Autism was enhanced by the development of rhythm, which they define as the establishment of rules, rituals and routines. The concept of rhythm (as a protective factor), for example, is a teachable skill that families with an Autistic child can learn and implement in order to strengthen their ability to manage their overall family functioning (Knestrick & Kuchey, 2009).

In reviewing the current literature, research shows an increase in the prevalence rate of Autism along with an increase in the prevalence rate of aggressive acts by youth with Autism. Mothers' caregiving efforts are impacted by the effects of Autism. Feminist Disability theory explains how mothers are also affected by their children's disability by proxy. The effects of marginalization and stigma are ongoing concerns for mothers raising children with Autism. Although some protective factors can enable mothers' ability to be resilient, these are affected by socioeconomic status. Listening to the voices of mothers of children with Autism and aggression through qualitative studies can provide insight into the support systems that can help these mothers to persevere.



## Methodology

Qualitative research methods are generally the method of choice by researchers adhering to the naturalist paradigm. Qualitative research is a field of inquiry in its own right. It crosscuts disciplines, fields, and subject matters. Qualitative inquiry represents a legitimate mode of social and human science exploration, without apology or comparison to quantitative research (Creswell, 2007). The purpose of this study was to learn about the experiences of mothers of children with Autism and aggression and to investigate the processes they undergo within their home, children's school, and community. Since my intent was to use the narratives of these mothers to explore these areas, qualitative research methods were the most appropriate vehicle to address their experiences.

### Naturalist Paradigm

A paradigm is a basic set of beliefs that provide a worldview and guide action. Paradigms reflect current views of the time and continually evolve (Creswell, 2007). Paradigms used by qualitative and quantitative researchers can vary based on their beliefs and their research goals. Qualitative researchers who subscribe to the naturalist paradigm study things in their natural settings, attempting to make sense of, or interpret phenomena in terms of the meanings people bring to them (Denzin & Lincoln, 2005). The naturalist paradigm developed by Lincoln and Guba (1985) is based on five basic beliefs, also referred to as "axioms." Each axiom answers a fundamental question from the naturalistic viewpoint and contributes to the foundation of this theoretical perspective. The axioms of the naturalist paradigm include the following: (1) a belief that there are multiple realities rather than a single universal one; (2) the relationship of the knower to the known is



interactive and inseparable' (3) hypotheses are time and context sensitive and not general; (4) causes and effects are constantly being shaped by the entities that surround them; and (5) the values of the inquirer are acknowledged and understood to affect the inquiry along with the chosen paradigm, theory and context.

Within the naturalist paradigm are characteristics that are used to guide the research methods of naturalistic inquiry. Among these are: data collection in a natural setting, researcher as instrument, qualitative methods of data collection (i.e., interviews, observation, survey), purposive sampling, inductive data analysis, grounded theory, emergent design, and negotiated outcomes (Lincoln & Guba, 1985). The research paradigm determines not only the approach or research methods used, but also the purpose of the research and the role of the researcher (Firestone, 1987).

Krefting (1991) describes qualitative research as the study of the empirical world from the viewpoint of the person under study. It fundamentally depends on watching people in their own environments and interacting with them in their own language, on their own terms. A qualitative study is credible when it presents such accurate descriptions or interpretations of human experience that people who also share that experience would immediately recognize the descriptions (Krefting, 1991). Qualitative research is conducted when a complex, detailed understanding of an issue is needed or when researchers want to understand the contexts or settings in which participants in a study address a problem or issue (Creswell, 2007). Qualitative researchers want to empower individuals to share their stories, hear their voices, and minimize the power relationships that often exist between a researcher and the participants in a study. The hallmark of qualitative research today is the deep involvement in issues of gender,

culture, and marginalized groups. The topics studied tend to be emotion laden, close to people and practical (Creswell, 2007). Through interviews and observation the researcher “sees” what actually happens in a given context, analyzes these social events, and interprets them for a larger audience (Cobb & Forbes, 2002).

All research is interpretive; it is guided by the researcher’s set of beliefs and feelings about the world, and how it should be understood and studied. Each interpretive paradigm makes particular demands on the researcher, including the questions the researcher asks and the interpretations he or she brings to them (Denzin & Lincoln, 2005). Denzin and Lincoln (2005) propose four major interpretive paradigms that structure qualitative research: positivist and postpositivist, constructivist-interpretive, critical, and feminist-poststructural. The constructivist-interpretive paradigm assumes a relativist ontology (there are multiple realities), a subjectivist epistemology (knower and respondent co-create understandings), and a naturalistic set of methodological procedures (which overlaps with the naturalist paradigm). Creswell (2007) describes the constructivist paradigm as *social* constructivism because the subjective meanings are negotiated socially and historically; they are formed through interaction with others and through historical and cultural norms that operate in individuals’ lives. Thus, the constructivist researcher addresses the “processes” of interaction among individuals. The use of a constructivist-interpretive lens may also lead to an appeal for change in which the qualitative project ends with distinct steps of reform and an incitement to action.

Because the constructivist paradigm best fits this researcher’s belief system and research interest, the current study was guided by the assumption that there are multiple, complex, and socially constructed realities. In examining and understanding the support

systems of mothers of children with Autism and aggression issues, the researcher served as the research instrument, making interpretations from the participant's perspectives and utilizing multiple methods to ascertain if a call to action was warranted.

### Design

The term "grounded theory" refers both to a method of inquiry and to the product of an inquiry. Grounded theory methods are a set of flexible analytic guidelines that enable researchers to focus their data collection and to build inductive middle-range theories and conceptual development (Charmaz, 2005). Grounded theory is theory that follows data rather than preceding it and is a necessary consequence of the naturalistic paradigm that posits multiple realities and makes transferability dependent on local contextual factors. Information that is gathered is used to build a model which serves to both describe and explain a system (Lincoln & Guba, 1985). Grounded theory contains tools to study how processes become institutionalized practices (Charmaz, 2005).

Charmaz (2005) posits that constructivist grounded theory adopts grounded theory guidelines as tools and emphasizes the studied phenomenon rather than the methods of studying it. In addition, constructivist grounded theorists take a reflexive stance on modes of knowing and representing studied life by locating themselves within these realities. Therefore, theoretical analyses are interpretive renderings of a reality, not objective reporting about it. Guba and Lincoln (2005) add that a significant portion of social phenomena consists of the meaning-making activities of groups and individuals around those phenomena. The meaning-making activities themselves are of central interest to constructivists simply because it is the meaning-making activities that shape

action (or inaction). The meaning-making activities themselves can be changed when they are found to be incomplete, faulty (e.g., discriminatory or oppressive), or malformed. Constructivist grounded theory focuses on learning about the experience within embedded, hidden networks, situations and relationships, and making visible hierarchies of power, communication and opportunity (Creswell, 2007).

### *Establishing Trustworthiness*

While there is no consensus on what or how many strategies should be used to develop strong qualitative work (Barusch, Gringeri & George, 2011), Lincoln and Guba (1985) established criteria for judging the rigor of a naturalistic inquiry, which they call trustworthiness. The four criteria for establishing trustworthiness include: credibility, transferability, dependability, and confirmability.

The most commonly used method of establishing credibility is through triangulation (Gliner, 1994). Triangulation is the simultaneous investigation and display of multiple realities (Denzin & Lincoln, 2005). This research project utilized triangulation of data methods and theories to establish credibility. First, interviews with participants were conducted in order to collect data grounded in personal experience. In addition, observations were made of the participants during this time, taking note of body language, emotions, and moments of silence. Finally, resilience theory and feminist disability theory were the theoretical lenses through which the experiences of the mothers were interpreted.

Geertz (1973) introduced the concept of thick description in order to establish and strengthen both data transferability and dependability. A researcher can achieve “thick

description” by not only documenting particular behavior but also recording the context of that behavior in order to enable interpretation of what that behavior means. Further, thick description involves rendering a deeply detailed account of one’s work so readers can judge the work’s potential for application to other times, places, people, and contexts (Barusch, et al, 2011). Because there is the assumption of multiple realities within the constructivist paradigm, identical replication is not the goal. Instead, a qualitative researcher intends to provide comprehensive documentation of the research process through thick description and is encouraged to conduct research audits with colleagues and/or advisors to identify sources of variation in experience (Krefting, 1991). Although the current study was not a traditional ethnographic design, the researcher attempted to achieve “thick description” by taking descriptive notes throughout the research process, documenting the contextual setting and specifics of each participant interview, noting the participants’ reactions as well as the researcher’s thoughts and reflections about the analysis process.

The last criterion of trustworthiness is confirmability or neutrality which is the monitoring of bias in the research procedures and results (Krefting, 1991). Confirmability is achieved through the use of peer examination and the regulation of research bias. Peer examination involves the researcher discussing the research process and findings with impartial colleagues who have experience with qualitative methods (Krefting, 1991). Peer examination is an opportunity for the researcher to present working hypotheses for reaction and to discuss the evolving design of the study (Lincoln & Guba, 1985). The thesis committee for this project provided assistance with peer examination. In order to monitor researcher bias, a research journal was kept throughout data collection and

analysis. In this journal, the researcher recorded her reactions, emotions, and thoughts about her role as instrument and interpreter of the research data. The purpose of the journal was not to entirely control research bias, as that is not possible, but instead to understand and monitor any existing bias in hopes of accurately representing the views and experiences of the study participants.

### Participants

Participants for this study were all mothers of children who have Autism that have demonstrated acts of aggression. An act of aggression was considered as hitting or striking with or without an object, biting or kicking another person, taking place at school or at home. Fourteen mothers ranging in age from 39 to 57 years old, with varying socioeconomic status were recruited from the northern New Jersey area (see Table 1). The majority of the mothers were Caucasian, two were Asian, and one self-identified as Middle Eastern. Their children ranged in age from 5 – 21 years old, with a mean of 13 years old across 11 males and 3 females. Criterion sampling was utilized to identify mothers appropriate for this study. The criteria for participation were the following: 1) having a child with Autism between the ages of 5 to 21 years old; and 2) this child had demonstrated acts of aggression at school or home, such as hitting or striking with or without an object, biting or kicking another person. Recruitment letters were distributed via email to local special education support groups and online parent support groups. Participants were contacted via phone to verify that their child met the above criteria and to confirm their interest in participating in the study. Interviews were scheduled at a time and location of the participants' choice and informed consent was acquired. Most

interviews took place in the home of the participant while two interviews took place in a local café. All interviews lasted between one and two hours and were audio-recorded.

## Data Sources

### *Interviews*

Interviews are central to data collection in a grounded theory study (Creswell, 2007). Interviewing is one of the most common and powerful ways in which researchers try to understand human experience. Interviewing is not merely the neutral exchange of asking questions and getting answers, rather, two (or more) people are involved in this process and their exchanges lead to the creation of a collaborative effort called *the interview* (Fontana & Fey, 2005). During the qualitative interview, researchers ask open-ended questions and listen to the participants in order to explore the phenomena they are investigating. A more open-ended, conversational interviewing style can generate more engaged personal narratives and more candid opinions. It also tends to humanize the interviewer and diminish their power and control over the interview process (Foley & Valenzuela, 2005). When researchers take an empathetic stance in favor of the individual or group being studied they become an advocate and partner in the study, hoping to use the results to advocate social policies and ameliorate the conditions of the interviewees (Fontana & Fey, 2005).

Interviews took place in a private area chosen by the study participants, and lasted between one and two hours. Participant identity was protected by the assigning of pseudonyms. Basic demographic questions were used to collect information about each



Table 1  
*Participant Mother Summary*

Name	Age	Ethnicity	Marital Status	# Children	Child Sex	Child Age	Education	Employed	Own Home	Advocacy
Donna	51	Caucasian	Divorced	2	Male	21	Masters	FT - Speech Therapist	No **	Yes
Tracy	45	Caucasian	Married	2	Male	13	College	No	Yes	Yes
Darla	54	Asian	Married	2	Female	21	College	PT - Financ. Consultant	Yes	Moderate
Lynn	42	Caucasian	Married	5*	Male	13	Some College	No	No	No
Natalie	51	Caucasian	Married	3	Male	14	Associate	No	Yes	Yes
Joan	46	Caucasian	Single	3*	Male	17	College	No	Yes	Yes
Karen	49	Caucasian	Married	1	Male	13	Doctorate	No	Yes	Moderate
Shalene	41	Caucasian	Married	1	Male	9	Masters	PT - Environ Scientist	Yes	Moderate
Tina	48	Caucasian	Married	2	Female	17	College	No	Yes	Yes
Patty	51	Caucasian	Divorced	2*	Male	18	Associate	PT - Health Aide	No	Yes
Heather	57	Asian	Married	2	Male	21	College	PT - Korean Translator	Yes	Yes
Sandy	42	Caucasian	Married	1	Female	7	Masters	PT - MSW Therapist	Yes	Moderate
Rose	49	Caucasian	Married	2*	Male	12	College	No	Yes	Yes
Agatha	39	Middle Eastern	Married	2*	Male	5	Masters	PT - Clinical Researcher	Yes	Yes

\* = Two or more children with Autism/Special Needs

\*\* = Lives with elderly parents in their home



participant, to understand specific Autism diagnoses (PDD, Asperger's or Autism Spectrum Disorder), as well as the sex and ethnicity of their child, and any medications the child was taking. The interview guide consisted of open-ended questions and was used with each participant to create a semi-structured interview process (see Appendix A). Topics in the interview guide included questions about home/community, school and social support. Each question on the interview guide was asked, however in addition to these questions, participants were encouraged to bring up topics that were relevant to their experiences. Questions guided mothers to address key areas that they could describe and expand to produce thick description. To explore feelings of isolation and marginalization that these mothers may have experienced, they were asked to describe an aggressive incident and to share how they felt when it happened and if or how any other family members responded or intervened. Questions to probe support systems within the school were asked such as "Describe how the school handles an aggressive episode involving your child" and "How does the school inform you of the incident?" also "Does the school offer any support or ways for you to get support for you or your child?" Often schools will call local police departments, who may have little or no training regarding children with Autism, to intervene when a child is aggressive in school. Questions to critically explore this process were used by asking mothers to describe how they felt about the police intervention and if the school prepared them for possible police intervention before an aggressive episode took place. Mothers had the opportunity to share what they wished the school would do differently to manage their child when they are aggressive, and to explore possible ways that mothers and their children could be supported within the school and police systems.

### *Observational*

Studies that rely mainly on interviewing as a data collection technique employ observational methods to note body language and other gestural cues that lend meaning to the words of the person being interviewed. Traditional cues such as gestures, facial expressions, and tones of voice all give nuances of meaning to social behavior (Angrosino, 2005). Creswell (2007) recommends designing an observational protocol as a method for recording notes in the field. Included in this protocol are both descriptive and reflective notes (i.e., the mood of the participant and impressions of the researcher) during the interview process. Because an important aspect of qualitative research is the context and how it influences behaviors, it must be fully and accurately described in field notes (Cobb & Forbes, 2002).

A research journal was used extensively during the interviews to make observational notes of the context of each interview, the emotions that related to the mother's experiences, as well as body language, and possible moments of silence and how these could be interpreted. Only a few interviews became emotional; not just for the mothers as participants, but for the researcher as well due to the researcher having had similar experiences with her son. As a result, following each interview I immediately wrote field notes about the overall interview experience such as the way the mother sounded (humorous, cynical or depressed) during the interview, her body language (tense or relaxed) and the appearance of her home.

### *Reflexivity*

Research is dynamic, and the researcher is a participant, not merely an observer. As a result, the investigators must analyze themselves within the context of their research (Krefting 1991). Guba and Lincoln (2005) describe reflexivity as the process of reflecting critically on the self as researcher, the “human as instrument.” It is a conscious analysis of the self as both inquirer and respondent, as teacher and learner, as the one coming to know the self within the processes of the research experience.

Reflexivity refers to assessing the influence of the investigator’s own background, perceptions, and interests on the qualitative research process. It includes the effect of the researcher’s personal history and the researcher’s background that may dictate the framework with which he or she will organize, study, and analyze the findings (Krefting, 1991). Researchers are not invisible neutral entities; rather, they are part of the interaction they seek to study and they influence that interaction. Some researchers are becoming keenly attuned to the fact that in knowing “others,” we come to know “ourselves” (Fontana & Fey, 2005). The use of self-reflective memos to document and enrich the analytic process is to make implicit thoughts explicit, which helps to expand the data (Creswell, 2007).

I kept a research journal of reflections during and immediately after each interview to examine any bias that I might have felt. I am keenly aware that my own personal experiences could have been similar to the ones being described during the participant interviews, yet new and completely different experiences were also described

which contributed to the data. I documented my own range of reactions and emotions and analyzed them along with the data generated from the interviews.

### Data Analysis

As a result of the inductive nature of this study, data were analyzed using content analysis within the context of the grounded theory method developed by Glaser and Strauss (1967). Grounded theory is a comparative method in which the researcher compares data with data, data with categories, and category with category. In this method, process, actions, and/or interactions are entered into codes that will then develop into themes or categories (Creswell, 2007). The initial coding phase in grounded theory forces the researcher to define the action in the data statement - codes are active, immediate, and short. They focus on defining action, explicating implicit assumptions, and seeing processes.

Content analysis involves the researcher categorizing and coding the data looking for common themes. The researcher assumes some codes of interest have already been discovered and described in previous research, and it is very likely that new codes will emerge (Denzin & Lincoln, 2005). This coding and analysis processes provide analytic scaffolding on which to build conclusions that can be formed into theory (Charmaz, 2005).

Interviews were audio recorded and transcribed verbatim. Data was coded by hand according to the themes and issues that the participants had experienced. Based on previous research of mothers of children with Autism, it was anticipated that themes of isolation and marginalization would be described. Themes of support or lack of support

systems offered through the school systems were highlighted. New and emergent themes were also noted as each interview took place, but due to time constraints, I had to adhere to the interview protocol and was not able to return to previous interviewees to probe new themes. Rather, they are noted as areas for possible future study. Research audits were conducted with the thesis advisor to assist in identifying emergent themes and analysis of the data. All codes were reviewed with the thesis advisor.

## Findings

*A mother's love for her child is like nothing else in the world, it knows no law, no pity, it dares all things and it crushes down remorselessly all that stands in its path.*

-Agatha Christie, *The Last Séance*

The purpose of this study was to investigate the experiences of mothers of children with Autism and aggression and to understand the processes they undergo with their children's school and the larger community. It was anticipated that themes of marginalization and depression would rise above other themes in the narratives of these 14 mothers. In actuality, although the mothers shared stories of marginalization and stigma, it did not overwhelm them as I expected it would. Instead, stories of endless determination, resourcefulness and love were told over and over. In addition, a coping process emerged which was developed by these mothers out of the urgent need to address the aggressive behaviors of their child with Autism. Hearing so many stories of aggression, harm, and injury was disturbing, but it was almost always off-set by an equal amount of resilience, love and commitment to their child. These mothers exhibited extraordinary strength and determination in the face of considerable adversity. One mother effectively described herself, as a "super-coper." As a fellow mother of a child with Autism and aggression issues, I left each mother feeling renewed by the sharing of her story.

Many mothers shared painful stories of marginalization and stigma, but remarkably, they did not allow these incidents to impact them directly. This is not because being marginalized and stigmatized did not cause them distress but because the needs of their child (or children) overshadowed all areas of their lives. They simply did not have time for the emotional pain of marginalization since addressing the needs of

their child required all their strength and most of their time. While a lack of knowledge of formal supports was found among these mothers, all of them had informal supports with fellow mothers of children with Autism with or without aggression. This contact was often a great sense of comfort for the mothers, along with a way to glean more information on behavioral techniques, medicines, therapies, holistic remedies, etc., which enabled their coping process. The narratives of the mothers described two outcomes of their coping process; they became advocates or they maintained a level of coping.

Following the analysis process, it became apparent that these mothers experienced a multi-stage coping process as a result of raising a child with Autism and aggression. This coping process model is comprised of four stages and within each stage are themes representing the mothers' experiences (see Figure 1).

#### Mothers' Experiences of Aggression, Marginalization and Stigma

##### *Acts of Aggression*

Each of the mothers included in this study had one or more children with Autism who also exhibited aggression. The generally accepted definition to describe aggressive acts is the presence of the intent to harm others. But it should be noted that when applying this definition to children with Autism, it may not be possible to truly know their 'intent' due to possible limited expressive language. Some children with Autism may commit an aggressive act due to an involuntary compulsion similar to a tic. Some of the participants' children committed self-injury in addition to injuring others, but for the purpose of this study, only situations that involved aggression towards others are discussed.

Some children with Autism and aggression will only be aggressive in certain environments, such as only in school or only at home. In order to ask the appropriate set of questions on the Interview Guide regarding these different environments (see Appendix A), the mothers were first asked if their child was aggressive more in the home, school or community or a combination of all three. More than half of the mothers answered that their child were aggressive in all three areas, with the remainder aggressing more in the home than in school or in the community.

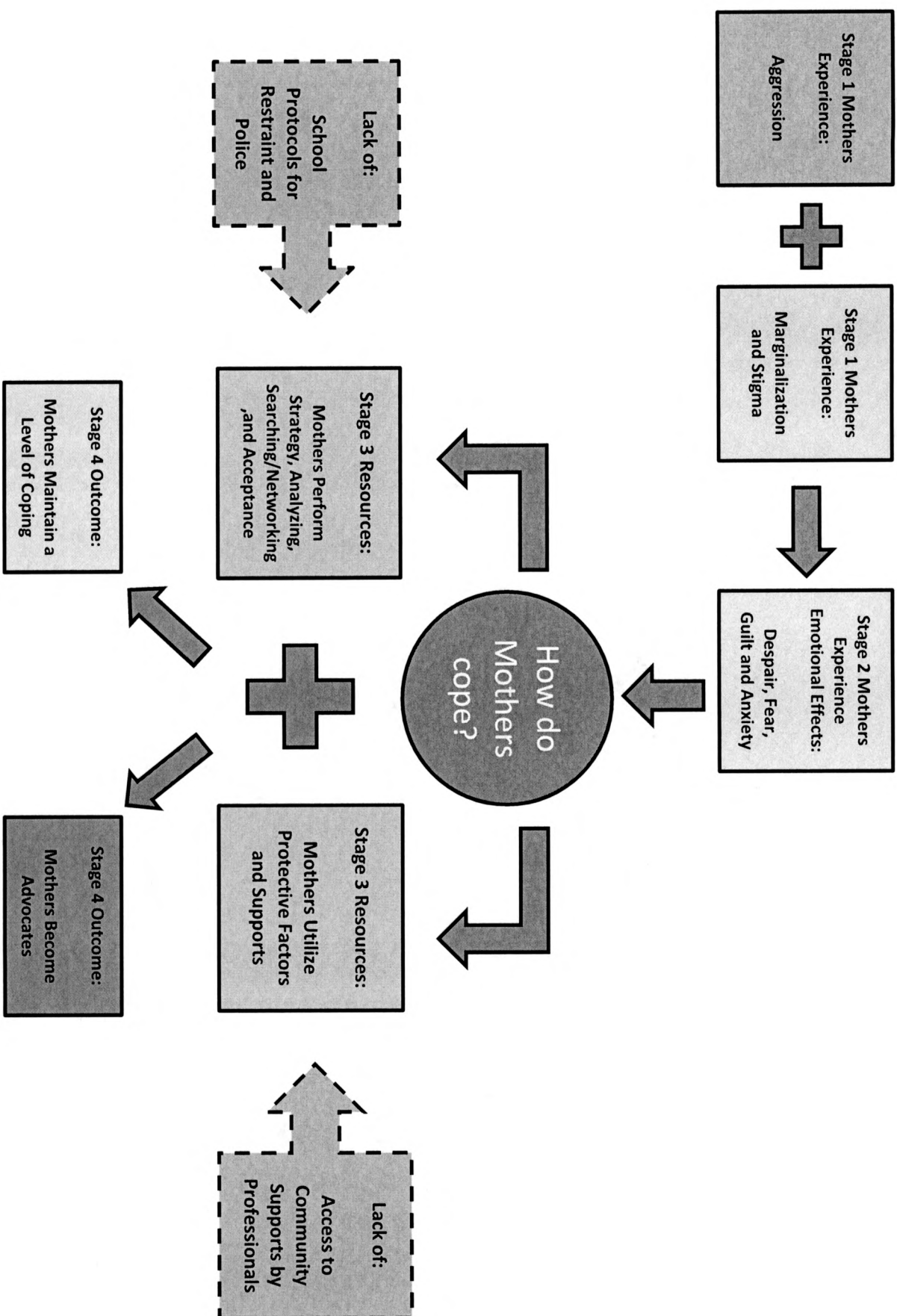
*Aggression in the home*

The 14 mothers who shared their experiences in this study did not appear to hold back, nor did I ever feel that I had to 'pull' anything out of them. When they realized that I was one of them, living the same range of emotions generated by my own son who has Autism and aggression, they immediately felt at ease and it was as if I unleashed a floodgate... they all willingly poured out their stories to me. The mothers shared many stories of aggression towards them or others by their children. These acts of aggression included biting, hitting, pinching and hair pulling. During the interview, mothers would point to their arms to show the scars and bruises they had received throughout the years. One mother, Heather, described how her son would try to poke her in the eye, which would usually leave scratches on her face. Karen described the aggressive tactics used by her 13 year old son throughout his younger years:

Because he was so violent, he was a master head butter...and these whole hand pinches, I had bruises up and down my arms. He broke one of my teeth with his head [when he] was as a toddler. Then the biting, the snotting, he could sort of



Figure 1. Process of Coping Model



blow snot at you from a distance, it was kind of amazing actually... spitting, everything.

Two mothers also described stories of hair pulling, sometimes while driving the car.

Tracy described how her son would attack her while she was driving the car, "if he can't reach and throw something at me, he'll have to get the aggression out and he would unbuckle [his seat belt] and pull my hair, while I'm driving." Similar to many of the mothers, Lynn described how aggression was becoming more challenging as a result of her son, now 13, getting bigger and stronger:

You tell him to do something and you try to physically lift him to go do what he has to do, like pulling him out of his bed, which is very difficult, then he'll swing at you, or kick you or hit your and become very verbal.

Rose described a serious incident that injured and frightened her, also as a result of her son's growing strength:

He almost broke my nose one time, I went to stop his hand and with his other hand he went like this (palm upwards to the nose) like an upper cut. If I didn't see it coming, he could've done that whole death blow thing to me, I swear.

Most mothers have not felt the need to call the police, although a few did share that they have considered doing so. Only one mother, Donna whose son is 21 years old, recently called the police when her son injured her badly. This was the first time he had injured her so seriously and the first time she ever had called the police. "I had to call the police, 'cause this time I was badly injured. I was thrown to the floor, my head hit the doorknob and he bit me so hard over here (shoulder), I was completely purple..."

The mothers also reported incidents where other family members were injured as well, including siblings, cousins, spouses, and elderly parents. Donna, a single parent who lives with her aging parents, expressed fear for her parents' safety during one of her son's rages. Additionally, Agatha, a mother of two, described her consistent fear for the security of her younger son. Frequently, her son with Autism targets his three and half year old younger brother, 'like just Saturday he bit his brother's face.'

*Aggression in the community*

In addition to managing aggression at home, the mothers described incidents of unexpected aggression happening in public. Because these attacks were often unprovoked and unanticipated, the mothers felt embarrassment as well as concern for the injured party. Shalene described an incident that was a direct result of her son's lack of impulse control but when it happened to an innocent child in the neighborhood, she admits becoming distraught:

The child was making a joke, not about my son just a joke in general, and my son can't handle jokes at all and he was like "Stop, stop, stop!" and he just broke the kid's arm...I was sobbing and both parents were incredibly amazing [about it].

Darla described a startling incident with her daughter at a rest stop, "and a child was crying and she just reached over and whacked her! And I was like, oh my god!" Rose also described her shock when her son bit a complete stranger in the thigh, "he just walked by her and took a chunk out of her leg, for no reason...The person was like 'Oh my God!' It was just like a rabid attack!"

Many of the mothers described these public acts of aggression and explained how their regular routines are particularly challenging. Because mothers, regardless of whether they have a child with Autism or not, frequently do the shopping and errands involved with running a home this may require they take their children out to public places. As a result, they have to learn to manage these types of outings with their potentially aggressive child. Shalene described how waiting in line at the store can trigger her son to become aggressive, "If it's just him and me, and if we're waiting in line, he'll start head-butting me and he'll start pinching me and that stuff." Patty, a single-mother, used the word 'apprehensive' to describe how she feels when taking her son to the grocery store after a particularly bad episode:

I said we have one more thing to get, you will wait and oh no... so he started screaming and yelling and hitting me, and beating me, and we ended up on the floor. Staff were all around us, clearing shelves....

She then went on to describe what mothers with Autism and aggression have to do when they take their children out of the home, "You're just more aware, and you really put that smile on your face and you keep that kid happy while you're doing whatever it is you have to do. So you're more...apprehensive [when going out]."

### *Aggression in Schools*

In addition to at home and in public, children with Autism and aggression also exhibited aggressive acts while in school. Joan described a violent scene by her teenage son "there was one time where he threw a desk at a teacher and knocked her to the floor and he jumped on top of her and he actually had his hands around her throat." Similarly,

Darla described a scene involving her 21 year old daughter during an end of the year ceremony that escalated quickly:

She was trying her damndest to get at one of the kids. Two rows of kids had to clear out 'cause she was knocking everything over and then she knocked down one of the teachers. I think she was the most aggressive kid in the school...

Some schools called the mothers the same day to report aggressive acts committed by their child. A few schools would report the incident via a "communication book" which is a book sent back and forth between the home and school documenting how well their child performed during the day, especially if the child has low functioning language. Almost half of the children in the study had been expelled from at least one school due to their aggressive behaviors. Although almost all the mothers expressed frustration with how the schools handled these situations, a few mothers reported feeling tremendous gratitude for the teachers and therapists that work with their children.

### *Marginalization and Stigma*

The mothers' experiences of aggression in the school, community and at home can lead to experiences of being excluded by friends and family and feeling judged by strangers. Ten out of the 14 mothers in this study experienced both marginalization and stigma by strangers in public as well as by family and friends due to their children's Autistic and aggressive behaviors.

Mothers described the complexity of maintaining relationships with friends and family. Because these mothers experience such severe ongoing stress, the ability to meet the reciprocal requirements of relationships is not always possible. As a result, they frequently experienced marginalization on a variety of fronts. Agatha explained why she

is no longer in contact with old friends, rationalizing that it is 'their loss' yet the undying love for her son shines through when she acknowledges that he is 'awesome':

I think they [old friends] are uncomfortable, they can't relate, and I certainly can't relate to them. And since they don't make the effort, I don't have time to make the effort. They think when you have a child with Autism it's this big scary, horrible, grieving thing, like he has cancer or something and they just avoid you I guess, and you know, it's their loss, because he's awesome.

Darla described feeling marginalized by neighborhood friends but also recognized that her daughter could not be around other children due to her aggression:

We were very, very close 'cause we all came into the neighborhood at the same time and we all had kids at the same time, but after a while it wasn't fair. I couldn't hang out with the girls or do things with them... 'cause when they started having birthday parties, my daughter was not invited, she couldn't be...

As a result of feeling marginalized, Karen described approaching her friendships differently. She now judges who she will become friends with very carefully, "I have to say through the years I have chosen friends carefully and some friends went away because of his behavior." In addition to feeling excluded by friends, the mothers described how family relationships were affected by the aggressive acts of their children. Tina shared a story about an act of aggression that occurred at a family holiday gathering. As a result of this attack, she and her sister-in-law are now estranged:

My sister in law's family is wonderful, but my daughter hit my sister in law's sister, I'm crying, my husband didn't want to eat, what kind of holiday is that? So I go nowhere now. You want to see me, you come here. My sister-in-law doesn't

get that. We have not exchanged gifts in a couple of years, she has normal children so she's not expected to understand.

Darla, whose daughter is now 21 and has a life-long history of aggression, used words such as 'alienating' to describe the effect her daughter's aggression had on her family and 'torture' and 'mentally harmed' to describe what the cousins endured:

It was an alienating thing, because we are a very close family. But it comes to a question of basic safety, not just physical safety, I mean these kids (cousins) were being tortured, they were being mentally harmed [by her daughter's aggression]. So, you know, you can't help but feel like... at one point I did feel like the world should accommodate her, but after a while you realize we have to protect the world from her.

A few of the mothers seem to accept the high price they must pay for this type of exclusion. These acts of marginalization by friends and family members left some of the mothers with a feeling of resignation, that there is no other choice.

In addition to being subjected to exclusionary acts by friends and family, these mothers also shared stories of social stigma when they felt judged by strangers while in public with their children. A number of the mothers continually felt the need to educate people in public about aspects of Autism and found this to be tiresome. Further, the mothers also emphasized their awareness of the quick judgments of others when their child became aggressive while in public, whether these judgments are verbalized or not.

Although most of the mother's dealt with disapproving glances and the judgments of others while in public, Rose and Darla shared stories of actual confrontations when



strangers verbalized their disapproval of their child's behavior, blaming them for the outburst. As Darla states:

I remember, we were in a restaurant and Maddie began to aggressively pound on a bathroom stall. I tried to get her to stop and the woman [in the next stall] became incensed. I started yelling at her back, I was like, 'she's Autistic what's your problem?!'

Rose has two sons with Autism, and while one has aggression issues, both boys can make loud, repetitive noises and try to run away from her while in public. She described her reaction to a hurtful statement made by a young woman she did not know:

And this bitchy little girl, maybe 20 years old, on her cell phone, and she stops, and says 'some people can't control their children' and my head exploded! And I screamed at the top of my lungs 'are you f-ing kidding me?! They're Autistic, what's your problem?!'

Rose also shared a story that demonstrated how stigma does not always consist of negative confrontations. Rather, the stigma she experienced took the form of excessive expressions of concern and sympathy by a well-meaning stranger. While these expressions may have good intentions, they only served to draw attention to her during her son's aggressive episode, triggering Rose to 'burst into tears:'

I've had strangers come up to me, like one time at Costco, he's hitting me and everyone is staring, and this lady came over to me and she puts her hand on my shoulder and said 'you're doing a really good job' and I burst into tears! I had another lady come up to me when things were not going well, and she gave me a



bracelet off of her wrist that had saints on it and she said 'this is blessed, I want you to wear it'.

This act is excessive and can be stigmatizing since the mother is already uncomfortable with the aggressive act happening in public.

All of the mothers emphasized that although they were experiencing the effects of marginalization and stigma, meeting the ongoing challenges of their child with Autism and aggression plus the needs of their other children, was paramount. Due to the constant urgency of the aggressive acts and meeting the many cognitive, social and sensory needs that come with Autism, they do not have the luxury of being impacted by this marginalization. They acknowledged that they took place and that it was upsetting, but they did not allow it to paralyze them emotionally because there was so much else to be constantly addressed. However, the *combination* of aggressive acts, effects of Autism and feeling marginalized did create a range of painful emotions experienced by these mothers. This range is categorized into four main themes of despair, fear, guilt and anxiety.

#### Mothers Experience Emotional Effects

Almost all of the mothers shared openly how much they loved their child and how committed they were to caring for them, even if it meant for the rest of their lives. These were strong emotions, which included the pain and frustration of raising a child impacted by Autism and behavioral challenges. These emotional stories are broken down into four main themes of despair, fear, guilt and anxiety, and all center around their child's Autism and aggression. It is important to note that these mothers shared stories of emotional pain

that cycled throughout the years of caring for their child and do not necessarily reflect their current situation.

### *Despair*

Key words or phrases that described the despair these mothers were experiencing include: hopeless, grieve, 'no end in sight,' felt like 'giving up,' 'at the end of my rope,' and periods of excessive crying. Lynn used the word 'grieve' to describe how she felt about her situation. She also expressed feeling envious of those that do not have to deal with aggression:

And you grieve 'cause your life is so hard, you feel like, why does it have to be so difficult? You look at other people and think why can't it be as easy as theirs is? And it frustrates me so much, 'cause other people just don't understand... they don't see what you go through....

Other mothers described periods of excessive crying during specific episodes or periods of aggression, as Shalene explained:

When he had his psychotic break, I was on the phone with my best friend and she said 'give him an over the counter sleeping pill,' which took 2 hours to work, it was an adult one too, 'and lock yourself in your bedroom.' And I did, and I cried, and cried, and I waited till it finished.

A few mothers described how the stress they felt could accumulate to where they needed a break but because there was none they had desires of escaping, as Rose stated:

It's a horrible, horrible place to be in your brain, I started a blog and started to write some of this shit and then it gets to the point where I don't even want some

of this stuff out there, because it's just horrible. You, just want to get in your car and drive away, and not come back.

Darla talked about reaching the "end of her rope" when her daughter's episodes became more alarming and dangerous over the summer as she awaited placement in a new adult day program:

Yea, I was done. Maybe 'cause it was right after this 2-3 week period where she was just with me all the time and I felt I was at the end of my rope. Then this behavior when she started to self-injure herself and then I had someone knock on my door and say 'there is a naked girl on your roof cleaning your gutters' ... [which was her daughter]"

Lynn shared her story about the times she wanted to give up working with her son, but ultimately she felt committed to teaching him responsibility:

But you just get to the point...you just want to give up, forget it, it's not worth the aggravation. But you are doing them a disservice, you are not teaching them responsibility, they're gonna have to know how to do, you know?

Mothers also described despair over the possibility that their child would always be violent and therefore not able to live in a group home and therefore would be living with them indefinitely. Many of the women acknowledged how bleak their futures looked since they would likely be caring for their children as they aged themselves. Rose admitted to feeling as if she has a life sentence, "When I'm 75 years old, what good am I? They'll kill me or break my hip or whatever. It's almost like a life sentence, so to speak."

## *Fear*

Out of the 14 mothers, half shared themes of fear but surprisingly this fear was not of being injured by their child. Their stories of fear centered mainly on authorities intervening and not understanding the situation, fear of their child aggressing in public, and fear of family members being harmed, mainly aging parents and younger siblings.

Key words used to describe fear included feeling nervous, afraid, and petrified, or phrases 'can't take the risk,' and 'walking on eggshells.' Two mothers spoke of fear of their child's aggression happening in public and described how they chose where they went with their child very carefully. Karen explained:

I got away with it until he was probably school age. I felt like I could get away with it [his aggression] and play on my anonymity...people [would think] 'Oh he's just a toddler having a tantrum.' But then he got older, and it became more embarrassing I would choose where I went very carefully.

Tina also spoke about taking her daughter only to 'safe places' that usually involved the homes of friends that 'understand:'

If I'm getting nervous to go someplace, I don't go, I only usually go to the safe places, like my girlfriend, where her son is the same age as my daughter. That's a safe place...I don't care if she's gonna have a meltdown. I try to surround myself with the people who get it.

Donna and Lynn expressed fear for the safety of their family members. Donna, who is a single parent and lives with her parents who are in their 70's has an Autistic son who is 20 years old and the size of a grown man. She worried he will injure her parents while she is at work, "The thing is my parents are too old and they are getting older. I can't risk

that he have another episode while I'm not at home." Lynn has five children and the oldest has Autism and aggression. She used an analogy of "walking on eggshells" to describe the fear she and the other siblings live with every day:

He will start fist-fighting with his brother and it turns into a bloody scene, she [the sister] will usually hide because she becomes a target. The little ones cry.

You don't know what... you're just walking on eggshells....

Other mothers were afraid of the unknown limits of intervention by professionals such as Child Protective Services or the police. Lynn had thoughts about calling the police when her son was aggressive but felt fearful about what they might do when they arrived, for example, take her son into custody, "I'm like 'let's call the cops' cause it will get to that point sometimes where he has my husband in a choke hold or pinned down...I haven't done it yet 'cause I'm petrified to call the cops." After she was injured by her son, Rose explained that she was afraid to go to the hospital for fear of officials being called and her son being removed from home:

I thought he broke my nose. He [husband] got me ice and I was so upset, that I was afraid to go to the hospital, because if I went to the hospital and I started spewing... I can't take it anymore blah blah... they probably would've come and taken him away from us, I was afraid.

### *Guilt*

The mothers expressed guilt over a number of situations related to their children's aggression. The first example was guilt over the impact of their child's aggression on their siblings. Specifically, they shared stories of guilt when their other children were injured by the aggressive child and over the long-term consequences of growing up in

such a stressful environment. They also worried about the responsibility they would potentially be placing on the siblings who would ultimately be responsible for their aggressive child. For example, Tracy felt the need to buffer the relationship of her older son with her aggressive son:

I want to find the right middle zone, the right blend of having my older son have responsibility over his brother. He has his whole life, unfortunately, to have responsibility over his brother. I'm sure at some point he is going to have way more [responsibility] than he ever wanted, so I don't want him to look back on his childhood and think, 'ugh, it was all about my brother and I had to take care of him, I had to rescue my mom,' he doesn't need that.

Tina also expressed guilt for her son who has to deal with his sister's aggression, so she described how she compensates by having him in therapy:

I always try to have someone available to him to speak with, since he was little, he did art therapy, just because. I don't want him to say 'you f'd up my life' by not getting me help, so I've always had people available to him.

Agatha's five year old son who has Autism and aggression deliberately attacks his three and half year old younger brother. She explained that this sibling aggression is her 'biggest challenge' and that it 'breaks my heart.' After her son deliberately bit his younger brother's face, she felt 'ashamed.' She described worry and guilt over the future emotional health of her younger son:

When it's aimed at me, I get upset, but of course when it's aimed at my younger son, I get so disgusted and angry and it's heartbreaking for me. I worry about him

and his feelings – the younger child. I really do worry about my younger son carrying a lot of this, um, kind of victimization around with him....

In addition to feeling guilty about the impact on their other children, mothers shared feelings of guilt towards the teachers who worked with their children at school. They felt responsible for their child's aggressive behaviors and used key words and phrases such as 'ashamed,' 'felt bad,' and 'apologize.' Tina was one of many mothers who shared her guilt about the teachers who work with her daughter, "I feel bad that she's doing that [aggression] to strangers, even though that's their job. I always feel terrible, like these people are amazing, who would want to do this job?!" Sandy also shared feeling 'bad' for the teachers who work with her daughter, and said she apologizes to them:

I mean, I felt so bad for those teachers sometimes.... it was definitely tough, there is always a part of me that's embarrassed. It's like, ugh god, I can't believe I have a kid that you have to deal with, I'm so sorry, and apologize for it.

### *Anxiety*

Like most mothers, the mothers in this study also experienced stress, but their stress was directly related to their child's Autism and aggression issues. Anxiety was used as a theme to represent feelings of distress, nervousness, and apprehension about a variety of daily struggles. Almost all of the mothers shared stories of distress directly related to their child's behaviors and the constant need to manage them. They also pointed to the anxiety they felt about the future prospects available to their children in terms of support, relationships, and being productive members of society. Finally, the mothers expressed distress due to the lack of help available in areas of childcare or

supportive help in the home. Key words or phrases used to identify themes of anxiety included worry, 'at wits end,' and fear of the 'unknown.'

Rose described her struggle with the randomness of her son's aggression triggers. She worked with the school to identify his triggers, but it was a constant struggle, since few triggers had been identified and this 'never knowing' when it would happen created stress in her ability to handle him at home. She used the term 'survival mode' when the aggression lasted for an extended period of time:

When he has the extended episodes of aggression, I can't even describe what my mind set is like then, because it is more of a survival mode, like 'let's just try to get through the day.' You have no idea what's going to happen, and you just want to make sure that he doesn't hurt strangers or hurt his brother.

Rose also described her distress at always being aware what her 15 year old son was doing or getting into, so she is not able to relax in her own home:

When I said it got harder when they got older, I meant 'cause the house is no longer secure. My son is too tall now, all these locks I have on things, on the door, he can reach and unlock and get out whenever he wants, so I can no longer just (exhale) breath out in my own house. I always have to have that ear open.

Shalene shared how she and her husband worry for her son's future, if he will become a 'productive member of society.' She did not express concern that he may live with her forever, but she did express anxiety about how her only child will relate with others, hoping he is not alone in the world:

All of our worry is – is he gonna be ok? Will he be a productive member of society? Will he be able to hold a job or a relationship? That's all we want, we



want him to love somebody, man or woman, we want him to have somebody that loves him and he loves, in the world.

As may be expected, concern about childcare was a serious source of anxiety for these mothers due to the challenging behaviors of their children. Karen used the word 'dilemma' to describe her anxiety over not being able to afford or keep sitters, due to her son's aggression:

So now I am looking for a job and my dilemma is that in my field, both as a performer and as a university lecturer or professor, you really need to be available in the evenings. And I really can't do it, it's just too difficult to find babysitting... I find that I have to pay at least \$20 an hour and they're often afraid of my son. I lose babysitters, it doesn't matter how qualified they are.

Mothers also spoke about the lack of help available when their child was raging and the stress this limited support caused them. As Lynn described:

We were at our wits end, we didn't know what to do... but to drive in the car with a raging child [to the police station], I mean, it's not going to do anything 'cause you just need help and you don't know what to do, 'cause there's just nothing.

Joan, a single parent of three children, two of whom have Autism, shared the distress of being out-numbered by her children particularly when aggression was taking place. She used sarcasm to express her jealousy of two-parent households:

I mean, there is one of me and three of them! I look at these two parent families with one challenging child, and I would never say anything to them, but I do think

it. I'm like, there's two of them [parents] so one can watch the kid and the other gets a break – what is that like??

The stories shared by these 14 mothers contained an enormous number of emotions being experienced, all centering on their day to day challenges of caring for a child with Autism and aggression. Their experiences involving harm and violence were intense and generated equally intense emotions. Narrowing down such intense emotional stories into four themes of despair, fear, guilt and anxiety was an attempt to compartmentalize emotions that often mesh together. These mothers are committed to their children due to their unconditional love, and the progress their children make drives them to find ways to cope so they can keep finding ways to help their children.

#### Mothers' Use of Resources

While listening to these mothers share the details of caring for their children with Autism and aggression, almost none of them appeared helpless, depressed, or ready to give up. Although they had periods in their lives when they were overwhelmed by these experiences, they all showed resilience combined with love and devotion. They shared amazing details of how they managed, or coped, with the taxing ordeal involved in raising aggressive children. The mothers spoke of endless battles with their school district, and with getting services from the state Department of Developmental Disabilities. For most of them, their success in these areas not only helped their child to succeed, but also empowered them to keep working. While many mothers of children with special needs worked diligently to help their children, there was more at stake for these mothers since the aggressive behaviors complicated the entire special education process and thus affected every area of their children's lives. For most of the mothers in

this study, it was not an option to just survive the battles with their children and the battles with the schools; they were compelled to find solutions. Their role as an empowered mother evolved into becoming their child's advocate.

Part of the reason these mothers' were so resilient was due to their ability to be resourceful. The stories they shared included inventive and creative ways to not just help their aggressive children, but improve their overall family functioning. It was impressive. Eventually, a process emerged that I could see enabled their ability to cope with their difficult situations. This 'process of coping' involved mothers forming strategies when going out in public, constantly analyzing the triggers of their children's behaviors, searching for techniques and remedies, and networking with fellow Autism mothers. These over-arching themes of resourcefulness continually appeared in these mothers' narratives. The degree of some of the mothers' resourcefulness varied, which appeared to be directly affected by their socioeconomic status (SES), protective factors and supports. While the resources utilized during this stage of the 'process of coping' were interconnected, each stage will be addressed independently.

### *Forming Strategy*

Having a child with Autism and aggression impacts the overall family functioning, yet each family has to continue with their daily tasks of living. In addition to the typical family responsibilities for these mothers was the need to manage their children's behavioral challenges while still going out in public and attending social events. The mothers shared stories about the ways they formed 'action plans' when running errands in order to deter a child's aggressive outburst or how they re-structured their days to meet the needs of their Autistic children yet deter aggressive episodes.

These mothers created multiple strategies just to get through their days and to enable their families to function on a daily basis. Key words and phrases used to identify ways of forming strategy included rearrange, reorganize, natural consequences, 'finding exits,' and 'buddy system'.

These mothers were only able to take their children out in public by forming strategies, based on prior successes and failures. They found ways to help their children manage potentially difficult experiences, like going to the grocery store, while still being able to accomplish the task of food shopping. Shalene, for example, developed a plan of action when taking her son to the grocery store, which included the buddy system, "we don't do the grocery store that much, I've been trying, a little bit...I usually try to take another child with me that he's buddies with, 'cause the child will actually be my helper with him."

Strategy can take the form of planning ahead and by understanding the limitations of the child's emotional and cognitive abilities. Shalene knew her son's ability to wait was limited, therefore, her strategy was to only tell him things as they happened "we usually don't tell him about stuff until we are doing it. Because everything is now, now, there is no being able to wait." When she spoke about taking her son out in public, Patty employed a strategy of planning for a quick exit if necessary, "you have no choice, whenever we went somewhere I found all the exits."

Rose also resorted to a 'strategy mode' when the school would call to inform her that her son was aggressing during the day. She would prepare to 'batten down the hatches' to get through the afternoon:

I start trying to gear myself up for what am I gonna do when they get home? Do I have to rearrange something, do I need to cancel what I was planning to do and just stay in? Or if a particular home therapist is coming over, I'm now texting them, giving them a heads up – 'ok we're having a day'. And just to try re-organize and 'batten down the hatches' so to speak, you know what I mean?

Mothers also used strategy to form the procedures and tactics they needed when an aggressive episode began. Tina and her husband purchased protective arm gear used by professionals in schools, which included a soft helmet for their daughter to wear when she began to self-injure (e.g., hitting herself in the head):

The gloves are more protective for us, and I have it in an Autism bag in the living room and when she starts, I say, 'you want Daddy to put the black gloves on? Or 'Do you want the helmet?'

Natalie also identified and used a specific strategy to deter her son's aggression. She would slowly back away or put a pillow in front of herself for protection when her son began to aggress. "The best thing we found was to just keep backing away, backing away, backing away or put a pillow in front of us, you know that kind of thing..." Darla knew that a small, dark room could help her daughter calm down, "I put her in her room and we hold the door, 'cause she doesn't stay. Usually, what she does better at, is to be in a small, dark room, quiet."

### *Analyzing for Triggers*

Most mothers will possess an innate ability to gauge their children's needs, emotions, and their behaviors. Most of the mothers of children with Autism and aggression are gauging their children's behaviors as a matter of protection; to protect

themselves, family members and strangers from being harmed by their child. The amount of analyzing that almost all of these mothers are doing is sheer detective work, since their children's triggers can change as they grow. Mothers uncovered various triggers such as sensory stimulations (i.e., loud music or open spaces), unexplained physical pain (i.e., ear or tooth ache), or misunderstanding of directives or questions. Many times the triggers were not clear to mothers or professionals. The constant analyzing for triggers of aggressive behavior was a prevalent theme shared by the mothers in this study. Key words and phrases used to describe the theme of analyzing are: 'figure it out,' pattern, trigger, and antecedent.

Mothers of children with Autism and aggression must analyze triggers constantly, both in the home and at school. Heather sums up the constant analyzing process, "it is a trial and error process, I wasn't born with this knowledge, if you are sensitive enough to pick up on his cues, then you get results." Agatha talked about how she sees a pattern of aggression in her son, "when he is aggressive, I can trace it back to a reason and I know I can correct it, because it is very predictable. I have seen this pattern over and over again." Natalie referred to the analyzing of her son's feelings as her 'analysis hat:'

Yea, my analysis hat is on and I'm trying to figure out what he's feeling and see what is going on. You don't always get an answer, but a lot of times you do, if you take a step back and let it happen.

Patty described how the process of analyzing for triggers is not only a constant demand but one that can take years to accomplish sometimes involving outside therapists:

Usually, unless it's hormonal, there is a reason why that triggers him. Now, two and half to three years, this went on, and I could not find the trigger. I had

therapists from DDD, all kinds of people saying, 'you have to find the trigger, you have to find the trigger'. The trigger is – in my situation which I finally figured out – I cannot yell. I cannot get upset, because he in turn does not feel safe, which in turn, he's scared so I get beat up.

Sometimes the analyzing process fails or the mother simply can't figure out what is causing the aggression. As Rose stated:

It's hard to see a trigger. We've done so many data sheets because they couldn't find a pattern. So you have to look and figure it out. And I'm sure you've seen this too, your kid is doing something crazy, and you're like, is this the Autism? Is there something physically wrong with him? Or is he just being a brat?

Because the aggression can also happen at school, the mothers had to communicate regularly with school professionals to analyze their children's aggressive triggers. Sometimes this partnership was successful but other times it was the mothers, due to their analyzing process, that provided detailed procedures that could be followed, or who pointed out where the school protocols were absent or not working. Tracy gave an example of how her son's behavior began to escalate at home and she was able to pinpoint that the cause was a lack of demands being placed on him at school. As a result, he became angry when asked to do something at home:

And all of sudden he stopped having aggression at school, but he was having a lot of it at home. I would go into the school and say, 'Huh, it's funny, he's not paying attention in class so he gets everything he wants all day long. No wonder why he's not pinching anybody! He's not really being asked to have to pay attention or do anything. You haven't taught him anything, so he's not aggressing!'



Mothers also shared their frustration when the schools were not responsive to their involvement or the suggestions they shared with regard to their child's behavior. Shalene, for example, devised a very detailed procedure for the school to follow; one that she felt could have really helped identify her son's triggers, but the school was not receptive:

I requested to them [the school], to give me a written document. I wanted to know the antecedent... how it was responded to...how that first try was met with Max. I wanted them to pull Max out of the environment and have a conversation to come to a solution. I had all these things that I wanted [in order] to see how it worked. I think I got that document, maybe once.

### *Searching and Networking*

For these mothers, helping their children with their Autism and aggression issues meant they needed to find answers. Answers could range from whether to use a biomedical doctor, to vitamin supplements, medications, behavior modification therapy or employing a holistic diet. Learning how to navigate the complicated Special Education system and knowing how to protect the rights of their children was a constant need. The searching and networking many of these mothers did was nothing short of relentless so it became a major part of their identity as mothers. These mothers shared stories of networking with professionals and with other mothers in online groups and in person. They attended workshops and they searched the internet for information. For many of them their knowledge became so vast, they sounded like 'experts' on different types of holistic and therapeutic treatments. Key words and phrases used to describe the theme of searching and networking include: resource, look up, read, informed, 'picking her brain,' and 'find out.'



These mothers told stories of coming in contact with professionals from the Autism community and many of them used the phrase 'picking their brain' to describe how they asked them questions looking for help for their children. As Tracy stated "one of my friends was a special education director for a while and she's a learning consultant now so I am always picking her brain." Shalene also shared, "I have a best friend, and her husband is also a principal, and they have three kids on the spectrum so I had the benefit of picking their brain and figure out what I needed to ask." Rose relied on a friend who was a special education teacher to get help with her children's Individualized Education Plan (IEP), "one of my friends is a special education teacher and she would help me understand IEP's and stuff and recently she went back to work and in an Autism school, so she is a good resource." Darla heard of a doctor in New York City and had other people contact him on her behalf so he would consider taking her daughter's case:

I felt like I could advocate for myself, if I really needed it. I mean I reached out to [name of the doctor] and he really didn't know me but I had lots of other people call him. (laughs) I knew enough people to get him to call me back. I felt like I had enough resources.

Mothers also discussed attending workshops on various topics that enabled them to help their children. Tina stated, "To help with the behaviors, we did the ABC's of behavior, the antecedent, behavior and consequence, that kind of thing. It was like a six week training, I drove all the way to Trenton for it." Joan also attended workshops on special education, "West Bergen has given me different information, like when I started having trouble with her IEP, they had a workshop on it and they gave me all the materials and they also suggested the respite for Jake."

Agatha discussed how she wanted to become the 'expert' on as many topics as possible that affected her son and often got this information by contacting other Autism moms. She admits it is a method for coping:

So two things I've done for coping, is getting help by getting in contact with other moms, just for that support, but also just studying and learning as much as I can so I can apply it to my son, so I can make decisions for him. I want to be the expert on everything, on ABA, on biomedical interventions, on the legal system, because I don't want to have to depend on anybody. Because when I depend on other people unfortunately they let me down.

Natalie also referred to her searching for information as a method of coping particularly after her son has an aggressive episode:

I go into research mode immediately. I start googling... I don't feel like I [can] allow myself to get into a space where I'm not being productive, so, I'm googling and finding things out about medical marijuana and homeopathy.

Mothers shared many stories about the searching process which was extremely time consuming. Many mothers spend years accumulating all of the knowledge they have as Joan described, "I mean, believe me I am one of the more informed parents that there is, at this point, but it's been an 11 year learning curve." Sandy listed a variety of vitamin supplements she researched and described a special diet that she gave her daughter after working with a DAN (Defeat Autism Now) doctor. All of the information she mentioned took considerable time to learn and understand:

A lot of vitamin supplements...and I have stuff I give her all the time, like fish oil, and vitamin D and something to help [with] folic acid which is usually low. And special vitamin supplement that I order from a pharmacy. She is on a special diet too... she is on a casin free and gluten free diet... all that stuff.

Sometimes mothers had to utilize their research skills in order to get the attention or cooperation of medical professionals. Mothers described how they struggled with doctors to get an Autism diagnosis or to find out the cause of their child's aggression issues. Tracy described how no doctor would say the word 'Autism' when her son was young until her searching confirmed her suspicions, "And then I started looking up ABA (Applied Behavioral Analysis) and boom – TA DA! No speech, no social stuff, delayed, low tone – equals Autism!!! It takes a genius to figure this out? It takes a parent to figure this out." Donna also described a situation where after considerable research she brought information to the doctor to help diagnose her son's recent raging, since she was determined to find out what was causing it:

So I was like, look, from what I'm reading it could be that he has an allergy to food, that's triggering migraines, and the migraine is triggering the episodes, but I want to get to the bottom of it. I don't want him to just be on medication, I want to find out what's wrong 'cause I just don't take this as an answer.

Donna was not satisfied with the doctor's response and re-affirmed her commitment to continue searching for answers:

[The doctor said] 'so there's really not much more we could do' ... I said well maybe medically there is not much more that you can do, but I will, I will search the ends of the earth to find an answer!

### *Reflection and Acceptance*

For some of these mothers, coming to a point of acceptance of their life with a child with Autism and aggression, was part of the coping process. Many of them shared stories of reflection that acknowledged the 'ups and downs' of having a child with Autism and aggression. They described working tirelessly to help their children and some were hopeful that their children would improve due to these efforts. They described coming to the realization that their child was all that mattered to them and as result they had to accept that the aggression and Autism characteristics were a part of their lives. Mothers shared stories of acceptance using key words and phrases such as: 'this is my life,' 'ups and downs,' 'used to it,' hardened, hopeful and redeeming.

Tracy demonstrated the complicated process that she experienced in coming to terms with her situation. She acknowledged that living with an aggressive child had become 'normal' for her family, but recognized it would not be considered 'normal' by most families, "You just kinda think, this is my life, this is what happens, this is so not normal. But for us it's normal." Natalie also described reaching a point of acceptance but emphasized despite the difficulty of getting there it is something a parent has to go through to fully understand where they are:

And no one is going to understand, unless they live it. Which is something we as parents we have to get to, 'cause you know what? I can't even ask anyone to understand it, because I wouldn't understand unless I was living it.

Some mothers seemed resigned to accepting their situation, acknowledging that they had become 'hardened' by it over the years. Tina described it this way, "I think I've become hardened over the years, like here we go again...versus walking on the eggshells type of thing, here we go again, here we go again...." Karen shared how she is no longer surprised by her son's aggression, "Well, on one hand, when you've lived with a child who's that aggressive for so many years, it's kinda like, oh again? Tell me something I don't know." Darla emphasized how accepting her daughter's aggression freed her to talk about it more easily, "It was only later, when it was very, very clear that it's not something I can avoid and it was just getting too hard to hide it. I don't really mind talking about it anymore, 'cause it's there."

In spite of the resigned acceptance that many of the mothers shared, there were a few that also remained hopeful that their children were improving. Sandy, a therapist in private practice spoke about her hope, basing it on the redeeming qualities she still sees in her daughter:

I would say, I am hopeful, because we've done SO much and she's come SO far. She has both sides, she can be amazing, and...two seconds later she is a monster. Somehow... I think that saved me...that she has this other aspect that is redeeming."

Part of the acceptance process for many of the mothers included coming to terms with the reality that they were the primary and likely only candidates to fully care for their Autistic children. Natalie described her situation with her son and the acceptance that she and her husband are the only ones that can truly help her son:

It just becomes your life, it's just your life. It's about him and he's the one that can't deal with the sensory and he's the one that can't deal with negative emotions, so we have to help him with that, we're the only ones that can help him with that.

### *Protective Factors*

There are conditions within the lives of all people that enable them to function and be resilient. Protective factors are circumstances or personal and environmental characteristics that provide the resources people need to continue living. The 14 mothers in this study possessed protective factors that enabled their process of coping. Socioeconomic status (SES) was one protective factor that 12 of the 14 mothers had in common. SES is a measure of an individual's or family's economic and social position based on education, income, and occupation (APA, 2013). Twelve of the mothers in this study enjoyed a higher level SES due to their college degrees, employment or the employment of their husbands. This financial security allowed them access to supportive resources such as health insurance, private therapy and doctor visits for their children when needed. These mothers were also able to hire attorneys when they needed to advocate for their children within the school district. Shalene described how all of their resources, including financial, enabled them to care for their son. Even the town they

chose to live in, due to its reputable school district, was chosen for her son, “Our whole lifestyle... we live in Ridgewood because of Mark, our finances go to Mark, we’re funding the alternative doctor and his camp and his therapies, everything is about Mark.”

Another protective factor that was discussed was the importance of self-care activities including prayer, exercise, meditation, yoga, massage, and personal hobbies. Donna shared how important her faith was when she was desperate to help her son, “I don’t know about you, but I pray and I pray and I was driving to work and prayed, God please help me figure out what’s going on with my son.” Sandy spoke about the variety of self-care activities she utilized in order to cope:

I exercise a lot, I meditate, I write, I paint, I play guitar...I have a lot of different things I do to help me stay calm. Like I am getting a massage later today. I do love self-care. It’s the only way for me to cope.

### *Supports*

Mothers in this study described many areas they turned to for support, with about half discussing the support of their husbands and about half utilizing formal therapy. Other areas of support discussed were family members, friends (non-Autism moms) and two mothers shared stories of support by school personnel. The largest support system mothers identified was fellow mothers of children with Autism, known as ‘Autism moms.’ All the mothers emphasized how important fellow Autism moms were to their coping process.

Most mothers felt seeing a therapist had helped them cope, not only with their child with Autism and aggression, but with other areas of their lives such as their

marriages. Tina shared that couples counseling had been helpful, “my husband and I go for marriage counseling and all this comes up, like how can we deal with this together if she has a meltdown, who takes over what...” Patty also described how therapy helped her when she experienced problems with both her sons and got divorced at the same time, “I was in therapy... I need BIG time emotional help. The same year his aggression started, my other son was abused and got kicked out of kindergarten and I got divorced within 6 months.” Joan, a single mother with three children, also felt supported by her therapist, especially when her mother died suddenly:

My therapist called me that Sunday afternoon, talked to me and said she would go into work an hour early the next day ‘cause she was fully booked. So she came in special just to see me... I would hate to ever have to change services ‘cause I just feel so well looked out for.

Lynn, who has five children – three of them with special needs, recently began seeing a therapist after being told she was having a nervous breakdown by the emergency room doctor:

The doctor is like, how many kids do you have? Tell me about this and tell me about that... and he was like, you are having a nervous breakdown, (laughs)... gee thanks. And he said that stress can manifest itself in so many physical ways, that you don’t even realize. But I knew this time, I was like either I’m gonna take myself to the hospital ‘cause I can’t take it anymore, or I’m gonna find a therapist, and I found a therapist.



Family members were also a source of support by mothers with husbands being mentioned the most frequently. The mothers who had support from their husbands, recognized it and openly stated how much it helped them, as Natalie stated, "My husband works from home, thank god. So we know if it's going to be a rough day or not but when it was really, really bad, we didn't leave each other alone, we stayed." Sandy shared how it took a while to get her husband to be 'on board' with her, and now they take turns dealing with her daughter:

I feel like we need the two of us, she is like having 3 kids sometimes... I would definitely say my husband is an incredible help at this point. She fights us and gets really mouthy and when I start to get ugh (heavy sigh), my husband jumps in, and when he gets it too much, I'm like, 'I got it,' so we help each other with that.

Agatha had high praise for her mother who although she was not born in America, follows her daughter's advice on how to address her son's Autism concerns:

My mother is amazing, even though she is an immigrant she reads everything she can. I tell her I want to put my son on a diet and she goes and becomes an expert on the GFCF (gluten-free casin-free) diet.

Rose shared how her sister started to come over one evening a week since Rose's husband is an accountant and was working long hours during tax season. Her sister continues to come 12 years later:

My older sister comes once a week and hangs out with us. It started when Andrew was a baby and I was so overwhelmed during tax season, that everyone felt bad

for me, 'cause I was just so tired. She's done it now for 12 years, she comes one night a week and she's Andrew's godmother and he adores her.

Only two mothers shared stories of receiving support from school personnel - a school nurse and a school social worker. Shalene received support when her son was acting up during a school event and Shalene became distraught:

First of all, the school social worker is like my therapist. So when shit was bad, when he had his break and all that, they had a family fun night at the school, and I brought Mark and he started kicking it up there too, and the social worker had me in a room and I was hysterically crying and she just kept talking to me and she's like this is what your gonna do... she is the one that told me about Child Mobile Response [CMR is a state agency that will come to the home within one hour after being called, to respond to a child with emotional or behavioral issues].

Interestingly, Shalene received this support information from a school professional only *after* her son was acting up during a school event and she became distraught. The social worker did not provide this information ahead of time, for example - during an IEP meeting.

Agatha also shared a story of receiving support from the school nurse, whom Agatha felt looks after all the special education students in the school, "The school nurse has been such a source of support, she gave me her home number, she calls me, she really looks out for my kids. I think she looks out for the special needs kids, especially." It is also noteworthy that this was the only mother who described feeling supported by the school nurse in her son's school.

All the mothers in this study mentioned how much they relied on the support of fellow mothers, most of them were mothers who also had a child with Autism, but not all had a child with Autism and aggression. Agatha, whose husband is not supportive of her efforts with her two sons, relies heavily on the support of her mom's group:

I would like to go on record to say my biggest source of support is my mom's group, my friends that I've met through this community. They're amazing people. I talk to them, we email each other 5 or 6 times a day on the group [list serve] and we try to get together at least once a month, but we're in communication on a daily basis.

Darla also spoke about depending on her online moms group for support, adding, 'ALL my friends are inside the Autism community:'

If I've have a bad night, I can go online to the listserve, and type blah, blah, blah and in the morning, [responses] will say "this is what you need to think about, its ok" and that's kinda nice. It's getting it out when you really need it even if its 1:00 in the morning, you can go online and just spew!

Tracy described the support she received from an organization called the Friendship Circle, which is for parents with children with special needs. She found these friends met her needs more than others, "Well I have so many to choose from now, through the Friendship Circle, we met SO many families, so many." Rose referred to her fellow Autism moms as her 'posse,' "I have a couple key Autism moms too, my little posse and we all get each other. Like you could send a really random, crazy text message to one of those girls, and they'll get it." Patty also spoke of a friend that is there for her at critical

times, “And she has jumped in here if I had to take anyone to the hospital, she’s at the hospital. I blink my eyes and she’s standing there, saying ‘go take a break,’ so yea, she’s very different.” Lynn stated how her one friend knows exactly what she needed, without Lynn having to say a word:

My one friend Sarah, she... I don’t even have to say anything to her, she knows exactly what I need. Like last night she called and lets go for a walk and get ice cream. She knew, she knows to pull me out, when I need to be pulled out.

Karen makes a point of stating that fellow Autism moms are the best support, but worries their support may be limited since they are dealing with the same issues as well, “But I’m finding the people who understand me are the other mothers and then you can’t tax them ‘cause they’re dealing with it every day too.” Natalie summed up how the support she receives from fellow Autism moms makes her feel like she is not being judged, “You relax, you actually feel relaxed, you don’t feel on guard all the time, not feeling like you’re being judged, you don’t feel like you have to make excuses for anything – ‘cause they live your life.”

*Outcome: Advocacy or Maintenance*

The process of coping utilized by the mothers in this study produced two outcomes of varying degrees: advocates and maintenance. The majority of the mothers appeared to be advocates for their children within the school and medical systems, utilizing resources and supports. Five of the mothers took this advocacy role further by becoming involved in advocacy organizations, serving as founders or board members of local parent groups. One mother in particular, Lynn, appeared to not be able to advocate

in the same way as the other mothers. This lower ability to advocate by Lynn seemed to be related to the fact that she has the most children (total of 5), and she also has the lowest SES of all the mothers in the study. Lynn simply did not have the resources and time needed to advocate and instead was only able to maintain a level of coping. She shared more stories of fear, anxiety and despair and the least amount of stories of resourcefulness. Lynn's despair is acutely apparent in the story she shared of going to the emergency room and being told she was having a nervous breakdown by the doctor. This event prompted Lynn to finally seek a therapist. While Lynn continued to maintain a level of coping, the rest of the mothers shared stories of advocacy not unlike research on mothers of children with special needs.

A majority of the mothers in this study shared examples of how they must continually advocate for their children with the school and medical systems and with society. Natalie summed up the never ending need to advocate since there is no clear way to navigate the multiple systems involved, "It's a double-edged sword, there is so much information out there and it gets tiring. Everything you need you have to fight for, and it's already in place for you but you're still fighting for it." Joan described her tenacity in dealing with her son's school system, "At the time they didn't offer me anything, but then I started making it clear that I wasn't going away quietly." Joan also jokingly added that she will stop at nothing if it will help her kids thus illustrating her commitment to advocacy, "Whatever it takes to get my kids what they need... (laughs) lying, cheating, stealing, I'm not above it to a degree. If they really need it, I am gonna get it for them." Many mothers shared emotionally charged stories of advocating during IEP meetings to

get what their children needed. Agatha shared how she finally got the district to move her son to a school better suited to meet his aggression:

That was when I went into the school and I said 'he is completely maladapted, that's it!' and I literally yelled at the case manager and said 'it's my job to protect my son, and it's your job to protect the other kids in the class.'

Sandy advocated for her daughter by sharing the details of her daughter's aggression triggers with the new teachers and requesting they speak to her previous teachers:

Well what I plan to do before school starts, is to write a letter about exactly where she is at, and what her issues are. I want them to talk to the old teachers she had, because they are incredibly well equipped to know what helps and what doesn't help.

Agatha shared how she advocates, in vigilante fashion, for her son when her cousin who is a doctor told her to accept her son's Autism:

I even have one stupid cousin who is a doctor and he started texting to me about acceptance, and I'm like, you're an idiot, I am not accepting anything. I am fighting this and we're gonna get through it and my goal is to help him lose his diagnosis, and I'm going to get as far as I can. I have to have that attitude.

Mothers shared stories of advocating for their child with society as well, as Natalie stated it's not sympathy that her son needs:

So that's another part of the advocacy is teaching people how to deal, and not let it be all-consuming, like poor me or poor them - poor them nothing! These kids are so incredible, it's this world that's wrong, its not them.

Mothers not only advocated for their child within the school and medical systems, but they also advocated with other Autism moms by sharing information. This is part of Agatha's coping process as she aptly described how becoming empowered leads to the solving of problems:

I encourage everybody to try to learn everything they can about everything!  
About nutritional interventions, about the most recent cutting edge science, the educational system and how to empower themselves, about what the rights are of their children. Because I think that's the only thing you can do, it's like, solving the problems relieves the stress.

These mothers' narratives demonstrated the many ways they cope with the challenges of raising a child with Autism and aggression by constantly analyzing for behavioral triggers. Their stories relay the overall utilization of resources, and the support of fellow Autism moms, but what is missing are the stories of receiving many of these resources and supports from the professionals in their lives.

#### Lack of Access to Formal and Community Supports by Professionals

These mothers were in regular contact with an extensive number of professionals. When a child has Autism, there are endless schools, doctors and therapists that a child will be required to see. It is assumed that the mother of the child with Autism will be present at all of these meetings and appointments, since she is most often the full time

caregiver of the child. Almost all of the children in this study were enrolled in out of district, private special education schools. Part of their child's education is the involvement of the Child Study Team which is in their home district and meets with the parents regularly throughout the school year. In addition to the teachers, case managers, psychologists and therapists accessed through their child's schools, many of these children also had private therapists working with them in their homes. Further, these mothers met regularly with a multitude of doctors to address many physical and emotional health aspects of their child's condition. The majority of these professionals were aware of the aggression their child was committing at school and at home, yet the support they provided with the aggression issues was nonexistent. When I asked the question "does the school or any professional offer support or ways to get help for yourself or your child?" many of the mothers laughed out loud and answered 'No, no one has ever said anything like that to me.' A few of the mothers added that they also never asked for help, as if the responsibility to access help lies solely on them, releasing these professionals of any responsibility to react to the physical and emotional distress that is taking place right before them.

What became apparent in my interviews, is that the mothers were not aware of the many formal supports that are available to them through community and state agencies. This is why they released the professionals of the responsibility of providing them access to these supports, because they didn't know they exist. These mothers only knew of the resources they found on their own, which were mostly identified via networking with fellow Autism moms.



These community and state agencies that offer ways for mothers to get help interact with the school's social workers and other professionals that are in direct contact with the mothers of Autistic children. School and social work professionals are aware of these local and state agencies, yet as these mothers revealed, no one provided them with this information. The clear disconnect between these mothers and their knowledge and access to formal support services was a significant finding in this study. For many families, especially lower SES families, schools are the first point of contact to the world of state agencies and government institutions. As a result, if these mothers are not learning about formal supports through the professionals at their child's school, then they do not know they exist and therefore, have no way to access them.

#### Lack of School Protocols Involving Restraint and Police

When a child is aggressive in a private special education school, teachers and para-professionals (aides) are trained to conduct a restraint hold on the child. There are different methodologies used, mainly Crisis Plan Institute (CPI) and Handle with Care. When restraint holds are done by a trained staff member, they are a safe way to keep the child from harming himself or others. Teachers and aides in public schools are not trained to use restraint holds and are not allowed by law to physically restrain a child. Some private special education schools also utilize a padded room, called a Quiet or Therapy room. This is a way for the child to finish raging safely, away from other children, furniture, computers, etc. What is not always clear is how the child is brought to the Quiet room when the aggression or raging begins. Generally it will take a few staff members to carry the child to the Quiet room, which can result in bruises on the child and/or staff during the transport.

As children with Autism grow, many of them become stronger and occasionally restraint holds are not adequate, so police may be called to the school. This is generally used as a last resort, for example, if the child uses anything as a weapon (pencil, scissors) or if school staff is harmed. When police intervention is required, it is not clear where the police jurisdiction begins and ends within school policy (e.g., what is the extent of force they can use on school grounds?). Further, police have little training on how to handle a child with Autism which only complicates their involvement. Police can be utilized to call an ambulance to transport the child to the hospital if needed.

Mothers were asked questions regarding how the school informed them if their child had been physically restrained at school and whether they were satisfied with this process. They were also asked how their school prepared them for a police intervention (e.g., exactly what constitutes needing to call police) and if they had thoughts about what the school could do differently. Three of the mothers in this study had young children and these questions did not apply to them. Nine of the other mothers shared their experiences and were able to answer these questions. Six of the nine mothers had children in schools that utilized a Quiet room.

Almost all of the mothers that had experience with restraint holds being used in their child's school stated they did not know this protocol was in place until *after* it was used on their child. While these mothers understand the need for using a restraint hold on their child, they were surprised they had not been informed of this protocol ahead of time. Only one mother, Karen, remembered signing a form at the beginning of the school year informing her of the restraint hold protocol. After signing this form, she was sporadically informed each time the hold was used on her son:

Mostly I would end up with phone calls 'he had a lot of trouble today, he had to go to the therapy room' something like that. But very little in writing. I had a lot of trouble getting things in writing... people basically don't want to put things in writing...

Some mothers were informed of the restraint hold being performed via phone while others were informed via letters. A few mothers had schools that use an 'incident' report, but many of them complained the school did not use it consistently, as Tracy stated, "When he went to the second classroom where he ended up getting expelled, I didn't get one all year. And I knew he was being restrained." For Joan, her son's school did not inform her that they use a Quiet room and she was shocked to learn of it afterwards:

But they didn't tell me there was a Quiet Room, I had no idea any of this could happen until I was called and told the first time that he was in it, I was horrified, I kept thinking about psychiatric hospitals from the 60's, you know...

A few mothers had excellent suggestions for how schools could inform parents when their child was restrained. Patty felt parents should be informed of everything that happened:

Absolutely I think it should be in a note, you should be called at the time of the incident and it should be the parents' call if they should come get them or leave them in that situation all day, instead of *maybe* get a call or *maybe* get a note. I want to be aware of everything.

Natalie felt strongly that the schools' fear of parents prohibits effective communication between home and school:

Yea, I think the protocol should be to let go of the darn fear about para professionals, at the end of the day, writing in that book exactly what happened, without a teacher approving it. I think they should stop looking at the parents as enemies.

Karen shared the same feelings as Natalie and Patty, wanting to know how they transported her son to the therapy room but acknowledging this request may be 'impractical:'

Well, it's probably impractical, but I think they should tell you in writing, who restrained him, the names, and how. I was never told exactly how they held him down, how did they get him on the floor, how did they get him to the therapy room?

All of the mothers had not experienced the school needing police intervention with their child. Except for Darla, none of the mothers ever had a discussion with the school about a protocol for possible police intervention. Darla remembered having a conversation with her daughter's principal that police could be called as a last resort, and the thought scared her:

I remember thinking, oh my god, will it come to that? Because the school supervisor said, we have to prepare you just in case, but it would be the absolute last resort. I remember that 'cause I was like you're not going to call them every

time she, you know, kicked somebody, 'cause they would be calling them five times a day.

The experiences of these mothers demonstrate the lack of consistency by schools to keep parents informed when their children are aggressive and must be restrained. Their experiences also showed that parents need to have the procedures involving police intervention explained to them ahead of time.

In summary, although overwhelming themes of marginalization and depression were expected among these 14 mothers of children with Autism and aggression, stories of resilience and coping were paramount. These mothers did share how the *inter-connected* experiences of aggression, marginalization and stigma resulted in feelings of despair, fear, guilt and anxiety. It was the combination of experiencing marginalization and acts of aggression that appeared to impact these mothers more than marginalization alone. The analysis of these qualitative interviews resulted in a coping process model that represents the mothers' use of resources that include forming strategy and analyzing behavioral triggers, along with searching and networking among their support systems who are mainly fellow mothers of children with Autism. The outcome of these mothers' process of coping was either becoming an advocate for their child or maintaining a level of coping which seemed to be affected by the protective factors that were present in their lives. Finally, the significant finding of this study was the lack of access to formal support services from the many professionals in the lives of these mothers. The lack of informing parents of restraint and police protocols by their children's schools was also noted. The implications of the process of coping outcomes and implications for school professionals will be discussed next.

## Discussion

The voices of the 14 mothers in this study illustrate the ways they have adapted to the challenges of raising a child with Autism and aggressive behaviors. The process of coping that emerged from their experiences supports research on the resourcefulness and resilience of mothers with children with disabilities, including Autism (Knestrick & Kuchey, 2009; Read, 2000; Rocque, 2010; Traustadottir, 1991). This qualitative study is the first, however, to go beyond documenting the impact of mothering an Autistic child to investigating the impact that aggression has on mothers who are also raising Autistic children. The difference between mothers raising a child with Autism and a mother raising a child with Autism and aggression is due to the nature of aggression itself; it requires immediate action when people are being injured or harmed. Society does not tolerate violent individuals, even if that individual has a developmental disability such as Autism (Gray, 1993; Hodgetts, et al., 2013). As a result, these mothers are forced to repeatedly react as they are responsible for finding any solution possible before their child faces societal consequences for their behaviors which can include arrest by police or possible incarceration.

In addition to the mothers' ability to adapt to the aggressive acts by their children with Autism, the experiences of the mothers in this study also support previous research on marginalization and stigma (Charmaz, 2008; Grassie, 2009; Ryan & Runswick-Cole, 2008). The emotional effects of despair, guilt, fear and anxiety that these mothers experienced is similar to previous research on mothers with children with Autism as well (Baker & Drapela, 2010; Boyd, 2002; Emerson, 2003; Rodrique, 2011; Sawyer, et al., 2010).

While not all children with Autism will display aggressive behaviors, research shows a 68% prevalence rate of aggression among youth with Autism toward their caregivers (Kanne & Mazurek, 2011), while a second study showed the rate dropping to 46% among 14 – 17 year old adolescents (Mazurek, et al, 2013). One study showed that families report the challenges of the aggressive behaviors outweigh the challenges of Autism on their overall family functioning (Hodgetts, et al., 2013). This effect can be seen in the experiences of these 14 mothers in the complexity of their coping process which includes the added level of being constantly vigilant in finding solutions to their child's aggressive behaviors. The impact of aggression on mothers is pervasive and these findings invite attention to promote strategies that provide access to support systems for mothers of children with Autism and aggression issues.

#### Process of Coping Outcomes

Despite the variation in their experiences, almost all of the mothers in this study shared examples of how they advocate for their child within the school system as well as in society. Some mothers advocated more strongly for their child, compelling them to extend their advocacy skills to help other parents with children with disabilities. A few mothers advocated for their children alone, getting the services their child needed. Only one mother in the sample did not describe advocacy as an outcome of her mothering experience or did so only partially. Lynn described how she was only able to maintain a level of coping. Lynn had the lowest level of socioeconomic status, living in an urban apartment with five children; the highest number of children compared to the other mothers in this study. Comparatively, the mothers who were able to advocate more effectively had only one or two children, owned a home and had an overall higher level



of SES. Lynn also reported the least amount of forming strategy and analyzing triggers and more feelings of despair compared to the mothers who were advocates, possibly due to her having less time to utilize resources. The effects of socioeconomic status on the mothers' ability to cope and practice advocacy efforts in this study support previous research on families' ability to be resilient (Knestrick & Kuchey, 2009).

### *Advocate as Identity*

As the results of this study indicate, mothers of children with Autism become their child's advocate formally and informally, making moral decisions and adjudications about crucial matters in the best interest of their child (Read, 2000). Rocque (2010) argues that mothers perform a proxy self-hood for their children, which also affects their identities as mothers. Mothers' mediation practices are vital for the formation and maintenance of positive identities for their children *and* themselves due to the shared lived experience of disability. The majority of the mothers in this study became advocates to varying degrees, some advocating just for their child alone and some becoming involved in organizations that provide activities for families with children with Autism. Four of the mothers that could be considered modest advocates, Sandy, Darla, Karen and Shalene, also have careers in addition to their caretaking duties. Their careers in counseling, finance, music, and environmental science respectively, also form their identities which may take precedence and limit their abilities to advocate in more organized ways.

The shared experience of disability empowers mothers to see the world from two distinct vantage points; that of a non-disabled woman and that of the proxy self-hood of



their child who is disabled. Women who may never have heard of the 'social model of disability' become convinced through their own experience that many of the most restrictive features of their own and their child's lives are not inevitable or necessary consequences of being disabled. They often believe that if only people were to regard it as important enough, many of those things could be changed and they and their children could have lives that are different and better (Read, 2000). Foley (2006) compares the searching and advocating done by parents of children with disabilities to the 'zeal of a mission' which provides feelings of purpose and determination that elevate the mood and restore hope. Such searching and advocating for change makes this absolutely essential for some parents to sustain the emotional endurance needed to persevere.

Researchers have referred to advocacy work by mothers of children with disabilities as 'guerilla warfare' (Read, 2000) and 'vigilantes' (Ryan & Runswick-Cole, 2008). The stories shared by Donna, Joan, Natalie and Agatha of how they will stop at nothing to get whatever their child needs, exemplifies how their job as mediator and ally becomes an almost inevitable extension of their role as mothers (Read, 2000). The amount of time and knowledge these mothers need in order to navigate these systems is considerable. This particular type of intimacy and involvement may well exceed that which occurs between mothers and their non-disabled children. The relationship, however protracted, is defined by and grounded in parent-child love and in many cases, may be energized by it (Read, 2000).

Some advocacy work by mothers of children with disabilities extends beyond their own child to a broader community or societal concerns. They begin to care what happens to people with disabilities in general and the way society treats them. Rose,

Patty, Tina and Tracy all shared how they were involved with community or school organizations, either as founders or board members that work to support families with children with disabilities. Traustadottir (1991) refers to this as the 'extended caring role' which is complex since raising a child with a disability can be extremely hard work that limits mothers in pursuing other roles and activities. At the same time, this role can also provide opportunities for mothers to extend their caring efforts to activities that are much more like a professional career than traditional mothering work. Mothers spend time advocating on behalf of their child and people with disabilities in general by going to meetings, lobbying legislators, pressuring the school board, and organizing parent groups. These are activities not typically pursued by females, but when performed by mothers of children with disabilities, they are seen as an extension of the mother's caring role and an expression of the mother's devotion to her child (Traustadottir, 1991).

#### *Effects of Socioeconomic Status as a Protective Factor*

Family resiliency does not develop through the evasion of risk, but through successful application of protective factors to engage in adverse situations and emerge from them stronger. Protective factors need to be assessed in context, as many influences may moderate or mediate their functioning (Benzies & Mychasiuk, 2009). The effects of family protective factors can be seen among the 14 mothers in this study. Family size and SES are two of the nine family protective factors needed to optimize family resiliency. An adequate income to appropriately support the family is a very important protective factor and is associated with a multitude of beneficial effects. The lack of protective factors are most notable in the narrative of Lynn. All the mothers except for Lynn had higher socioeconomic status (SES) and smaller family size. The findings in the current

study support the research by Knestrict and Kuchey (2009) who found that the level of income and access to resources is the controlling factor in the pursuit of family resilience. It affects the family's ability to access resources, where they choose to live, what schools they choose to send their children to and to what type of medical care they have access. They also found that higher SES translated into more time available during the day. Higher income provides a higher level of resources available to parents, thus they require less time, effort and energy to access these services. This also allows parents to have more time to reflect on their child and enables them to think of disability differently by putting the child first and disability second in the context of their family functioning.

The experiences of all the mothers in this study were directly affected by their level of SES. All of them were able to provide medical care to their children as well as gain access to adequate school districts that provided special education services. Almost all of the mothers were able to be home full-time or work only part-time, which provided them with the time to search resources and supports including ways to advocate for their child.

#### Implications for School Professionals

A significant finding in this study was the mothers' lack of access to formal and community supports by the many professionals in their lives. While these professionals, especially in the schools, were aware of the aggression and injury that was being committed by each child, none of them ever asked the mothers about their own well-being, for example, "Are you alright?" or "Are you getting help?" Many of these mothers were extremely resourceful, but because aggression is such a serious issue, it is critical

that mothers have support available to them as opposed to having to seek out assistance on their own. School professionals that knowingly come in contact with a family that is experiencing aggression should be obligated to offer access to formal and community supports to assist the mother in her caregiving efforts.

*New Jersey Professional Standards for Teachers*

In the decade review of research on support for families of children with disabilities, Canary (2008) highlighted two studies on the topic of professional support relationships. These two studies indicated that school-related professionals feel constrained in providing the emotional support desired by parents due to bureaucratic structures of support agencies, overwhelming caseloads, and confusion about whether they should be providing more than instrumental support. Mothers of children with disabilities reported that they viewed their relationships with medical professionals and other formal support providers as generally combative and that they often struggled to get services they needed for their children *or themselves* (Canary, 2008). Two themes emerged from the studies reviewed by Canary (2008), first, confusion exists among professionals and parents alike as to relational boundaries and type of support that should be expected or provided. Second, positive, supportive, professional relationships contribute to positive child and family outcomes. The finding on the lack of access to formal and community supports by professionals in the lives of the mothers in this study supports the review of research by Canary (2008). What appears to be missing is simple communication in the form of providing access to supports. Formal and community supports are offered by county and state agencies; school professionals simply need to

communicate that they exist, by providing a phone number or a brochure to mothers who may need support in caring for themselves and/or their child with Autism and aggression.

Examples of community and state organizations in New Jersey that are available to support mothers and children with behavioral challenges is the Children's System of Care (CSOC) which includes Child Mobile Response (CMR), Family Support Organization (FSO), and Mom 2 Mom. Child Mobile Response (CMR) will respond to a behavioral crisis involving a child under the age of 21 within one hour. They can provide transportation to the hospital and/or provide up to eight weeks of stabilization and case management for the family. Family Support Organizations are located in every county and offer wraparound services and supports to help families that have a child with emotional and/or behavioral challenges. And finally, Mom 2 Mom is part of Rutgers University and is a 24 hour, 7 day a week, toll-free helpline staffed by trained mothers of children with emotional and behavioral challenges. In addition to the helpline, they offer clinical assessment of mothers, regular phone support and monthly support groups. All of these community and formal supports are offered free of charge.

Canary (2008) noted the confusion of professionals to provide the emotional support desired by the mothers and how mothers struggle to get services for their children and themselves. The confusion on the part of school professionals may be addressed by the New Jersey Professional Standards for Teachers and School Leaders. Adopted by the state Board of Education in December 2003, the Professional Standards for Teachers and School Leaders is part of the new licensing regulations. These eleven professional standards provide a clear vision of the knowledge, performances and dispositions that teachers and school leaders need to support educating students as called for in the revised

Core Curriculum Content Standards (NJ DOE, 2004). Standard Nine discusses collaboration and partnerships that teachers and school leaders are expected to formulate, “Teachers shall build relationships with parents, guardians, families *and agencies* in the larger community to support students’ learning and well-being” (p. 17). Standard Nine furthers this relationships concept, “Institute parent/family involvement practices that support meaningful *communication...*” (p. 17). School professionals in New Jersey need only to refer to their own state licensing standards to dispel any confusion about their expectation to form relationships and communicate to families, which includes mothers of children with Autism and aggression, about the community and state support systems that are available.

A lesser finding uncovered due to the questions on the interview guide was the mothers’ lack of knowledge of possible police intervention and restraint procedures used by the schools. If schools had restraint and police protocols in place that could be discussed with parents ahead of time, this discussion could provide an opportunity to share other forms of support. This would enable schools to identify these parents *before* they are in crisis and need community and state supports. In turn, this would enable mothers to be emotionally prepared for the protocols before they are utilized by the school and have the resources available should they need support in the home or for themselves.

#### Limitations and Future Research

There are several limitations in this study. The first relates to the small sample size of 14 mothers and the fact that the results are not generalizable to the entire

population of mothers of children with Autism and aggression. The relatively high level of education and SES is also a limitation of the study along with the lack of ethnic diversity of the mothers. Despite these limitations, the current study makes a critical contribution to our knowledge of how mothers experience the effects of aggression when caring for children with Autism and behavioral challenges.

Future research can explore ways in which professionals can provide access to community and formal supports for mothers of children with Autism who may be experiencing aggression in the home or school. Future research is needed on how schools can design a protocol that can inform parents when restraints will be used on their child with Autism and aggression and when police intervention is required by schools. In addition to further research on how school personnel can support the families of students receiving special education services, other research shows that school nurses are in a 'prime position' to assess the levels of stress on caregiving parents (Luther et al., 2005). The school nurse is in a position to identify potential and existing problems and assist with appropriate interventions for families of children with Autism and aggression concerns. Assessment of parental concerns by the school nurse could help parents feel more supported (Luther et al., 2005).

### Conclusion

This qualitative study explored the experiences of 14 mothers who have children with Autism and aggression issues, by recording and analyzing their narratives. Themes of despair and marginalization were anticipated but instead the combination of marginalization, stigma and the impact of aggression were found to be the overarching



themes. Using grounded theory, a process of coping emerged from their narratives of how the mothers search and utilize resources. Upon further investigation, mothers noted how they receive very little supports from the professionals in their lives, including school personnel. A lack of consistent protocols regarding when their child is restrained in school and possible police intervention was also noted by these mothers.

Mothers raising a child with Autism and aggression are in need of support so they can continue to provide the care necessary to help their children gain their full potential. This is a daunting task for these mothers, with overwhelming obstacles in their respective paths. By researching their experiences we can gain valuable insight into their specific needs and create the foundation of support they must have in order to achieve success. Schools and professionals are in a position to provide access to support and by exploring the narratives of these mothers, direction can be provided to improve existing institutional practice.



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Appendix A  
Interview Guide

General Information:

1. Sex, ethnicity and age of child.
2. Mother's profession? Currently working at paid employment full or part time?
3. Official diagnosis? (Autism, Asperger's, PDD-NOS, ASD).
4. Current/past school placement? (out of district school, self-contained class in public school, inclusive class, private school, residential school, home schooled, graduated, college, day/work program).
5. Current support services used? (DDD, DCF, DVR, behaviorist, therapist, mentor, recreation/social activities, in/out home respite, family members).
6. Does your child take any medications for aggression?
7. At what age was your child's first aggressive episode?
8. Have you been trained to use restraint holds? If so, who taught you? (school faculty, behaviorist, therapist, Handle with Care professional).
- \*8. Does your child have aggressive episodes only within the home, school or community or a combination of all three? (If answer is only in one area, skip to questions for that area.)

\*Home or Community:

- 1 Describe what happens when your child has an aggressive episode at home or in the community.
  - A. Describe how you feel when this happens.

B. How do other family members respond?

2 Do you feel that you are able to handle an aggressive episode alone or do you feel that you need help? How do you handle it?

3 What does your child's future look like to you?

A. What do you wish you could make happen?

\*School:

1 Describe how the school handles your child's aggressive episodes.

A. If they are physically restrained, how does the school inform you?

3 Describe how you feel when you have to talk to school personnel after your child has had an aggressive episode.

A. How satisfied are you with this procedure? How could it be improved?

B. Does the school offer any support or ways to get help for yourself or your child?

4 If the school has called the police for assistance with your child's aggressive episodes, describe what happened when the police arrived.

A. How did the school prepare you for a possible police intervention?

B. How did you feel about the police intervention?

5 How would you like the school to handle an aggressive episode with your child?

A. What do you wish the school would do differently?

Social Support:

- 1 What types of emotional supports are in place for you when your child has an aggressive episode?
  - A. Is there anyone in your family or community that you can call to help you?
  - B. If not, what or who do you wish you could call for help?
- 2 Have you ever received any formal counseling, either for yourself or your family?
  - A. What types of assistance did they recommend? Do you feel that it helped or not?

## Appendix B

## Recruitment Letter

I am a graduate student at Montclair State University in the Department of Family and Child Studies. I am doing a study on mothers of children with Autism who have also been aggressive toward other people.

I would like to interview mothers that have a child between 5 -21 years old. These children have been aggressive more than once. The aggression can happen at home or at school. Aggression is striking, hitting, kicking or biting another person.

By taking part in this study, you will help others in the future. Interviews will be held from May 2013 through August 2013. The interview should last 60 minutes.

All information you share will be kept confidential. There is no cost to be in this study. You will not be paid to be in this study.

It is possible that you will become upset while sharing your experiences about your child. If you should feel upset during the interview, you can choose to take a break or to stop the interview. Participation is voluntary.

For more information about this study, you can contact the Institutional Review Board at Montclair State University at 973-655-7583.

If you would like to be interviewed for this study, please contact me by email or at the phone number listed below.

Thank you!

Christine Peters

Graduate Student  
Montclair State University  
201-289-0765  
[petersc1@mail.montclair.edu](mailto:petersc1@mail.montclair.edu)

Dr. Christine Price

Faculty Sponsor  
Montclair State University  
973-655-3358  
[pricech@mail.montclair.edu](mailto:pricech@mail.montclair.edu)



## Appendix C

## IRB Approval



**MONTCLAIR STATE**  
**UNIVERSITY**

**Institutional Review Board**  
**College Hall, Room 248**

VOICE: 973-655-7583  
FAX: 973-655-3022

March 25, 2013

Ms. Christine Peters  
231 Bell Ave  
Hasbrouck Heights, NJ 07604

Re: IRB Number: **001298**

Project Title: **Experiences of Mothers of Children with Autism and Aggression**

Dear Ms. Peters:

After a Full 4 & 8 review, Montclair State University's Institutional Review Board (IRB) approved this protocol on **February 20, 2013**. The study is valid for one year and will expire on **February 20, 2014**.

Before requesting amendments, extensions, or project closure, please reference MSU's IRB website and download the current forms.

Should you wish to make changes to the IRB-approved procedures, prior to the expiration of your approval, submit your requests using the Amendment form.

For Continuing Review, it is advised that you submit your form 60 days before the month of the expiration date above. If you have not received MSU's IRB approval by your study's expiration date, ALL research activities must STOP, including data analysis. If your research continues without MSU's IRB approval, you will be in violation of Federal and other regulations.

After your study is completed, submit your Project Completion form.

If you have any questions regarding the IRB requirements, please contact me at 973-655-5189, [reviewboard@mail.montclair.edu](mailto:reviewboard@mail.montclair.edu), or the Institutional Review Board.

Sincerely yours,

A handwritten signature in black ink, appearing to read "Katrina Bulkley".

Dr. Katrina Bulkley  
IRB Chair

cc: Dr. Christine Price, Faculty Sponsor  
Ms. Amy Aiello, Graduate School

[montclair.edu](http://montclair.edu)

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Appendix D  
Consent Form page 1



# MONTCLAIR STATE UNIVERSITY

1 Normal Ave, Montclair NJ 07043

*College of Education and Human Services*

Department of Family and Child Studies

Voice: 973-655-4171

Fax: 973-655-6795

## CONSENT FORM FOR ADULTS

**Please read before signing.**

**Study's Title:** Experiences of Mothers of Children with Autism and Aggression

**Why is this study being done?** To learn what mothers of children with Autism and aggression experience at home and in the schools. Also, to learn what support they have available.

**What will happen while you are in the study?** You will be asked about your child's aggression. You will be asked about any help you get with your child. This interview should take 60 minutes. The interview will be tape recorded. The audio tape will be transcribed. The audio recordings will be destroyed after they are transcribed. All information you share will be kept private. You will be given a fake name so only the interviewer will know you.

**Time:** This interview will take about 60 minutes.

**Risks** There is a chance you may feel upset while talking about your child. If you should feel upset, you can take a break or stop the interview. If you need support after the interview, you can call Care Plus NJ at 201-265-8200. They offer counseling on a sliding scale. They take most health insurance and Medicaid. You can also get free counseling from Mom 2 Mom by calling 877-914-6662 or go to [www.mom2mom.us.com](http://www.mom2mom.us.com).

**Benefits:** The benefit is to gain new knowledge. If you take part in this study, you may help other families in the future.

**Compensation:** You will not be paid for being in this study.

**Who will know that you are in this study?** Only the interviewer will know you were in this study. New Jersey law requires that any person who suspects a child has been abused must report it to the authorities.

**Do you have to be in the study?** No, you do not have to be in this study. You do not have to answer any questions you do not want to answer.



Appendix D  
Consent Form page 2



# MONTCLAIR STATE UNIVERSITY

1 Normal Ave, Montclair NJ 07043

*College of Education and Human Services*

Department of Family and Child Studies

Voice: 973-655-4171

Fax: 973-655-6795

**Do you have any questions about this study?** Please contact:

Principal Investigator:  
Christine Peters  
231 Bell Ave  
Hasbrouck Heights NJ 07604  
201-289-0765  
[peterscl@mail.montclair.edu](mailto:peterscl@mail.montclair.edu)

Faculty Sponsor:  
Dr. Christine Price  
Montclair State University  
1 Normal Ave  
Montclair NJ 07043  
973-655-3358  
[pricech@mail.montclair.edu](mailto:pricech@mail.montclair.edu)

**Do you have any questions about your rights as a research participant?** Phone or email the IRB Chair, Dr. Katrina Bulkley at 973-655-5189 or [reviewboard@mail.montclair.edu](mailto:reviewboard@mail.montclair.edu).

**Future Studies:** It is okay to use my data in other studies  
Please initial: \_\_\_\_\_ Yes \_\_\_\_\_ No

**Study Summary:** I would like to get a summary of this study  
Please initial: \_\_\_\_\_ Yes \_\_\_\_\_ No

**It is okay to audiotape me while I am in this study:**  
Please initial: \_\_\_\_\_ Yes \_\_\_\_\_ No

**One copy of this consent form is for you to keep.**

**Statement of Consent**

I have read this form. I agree to be interviewed. The purpose and risks have been explained to me. I understand that I can stop at any time. I am 18 years old or older and have been given a copy of this consent form.

\_\_\_\_\_  
Print your name here                      Sign your name here                      Date

Christine Peters \_\_\_\_\_  
Name of Principal Investigator                      Signature                      Date

Dr Christine Price \_\_\_\_\_  
Name of Faculty Sponsor                      Signature                      Date

